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# SWEET *Louise*

***A guide to life  
with secondary  
breast cancer***



# About Sweet Louise

Auckland woman Louise Perkins was diagnosed with secondary breast cancer at the age of 29. However, this did not stop her from living life to the full for over ten years. Her philosophy of doing something positive for herself every day laid the foundations for Sweet Louise, a unique charitable trust with the primary purpose of improving the quality of life for New Zealand women and men living with secondary breast cancer.

Sweet Louise Members can redeem an annual allocation of vouchers for a wide range of contracted practical and therapeutic services approved by a Medical Advisor and designed to enhance overall well-being.

Support Coordinators assist with access to both Sweet Louise and other community services and can be 'someone to talk to' about quality of life and the day to day challenges of living with an incurable illness.

Sweet Louise fills a real gap in the lives of its members by offering practical support, connections and the companionship of others sharing similar experiences.

**“As long as I’m with Sweet Louise I don’t feel alone – and cancer is a lonely disease. Whatever you need at that time, they will provide.”**

Jenna

**For more information, visit [www.sweetlouise.co.nz](http://www.sweetlouise.co.nz)  
email [members@sweetlouise.co.nz](mailto:members@sweetlouise.co.nz)  
or call toll free (within New Zealand) on 0800 11 22 77.**

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This information book is a guide only, intended to help you understand some aspects of your treatment and care for secondary breast cancer and to inform you of the services offered by Sweet Louise. It is not a substitute for medical advice and at all times you should consult your medical team for expert information regarding your treatment options.

# ***Acknowledgments***

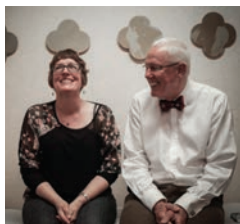
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# Foreword



I have been fortunate to help care for women with breast cancer over 40 years. During this time I have been involved in many clinical trials, which have led to significant improvements in the cure rate of early breast cancer. Despite these successes, there remain many challenges and frustrations.

Secondary (or metastatic) breast cancer remains incurable, though control is possible for many patients over increasing periods, sometimes for a number of years.

One of my proudest achievements has been my association with Sweet Louise. During Louise's 10 years with breast cancer, she became a friend and showed me that even with secondary cancer it is possible to live well and enjoy life. Louise was lucky to have the means to do things that most patients cannot afford. When her husband Scott, my wife and I sat one evening at their Waiheke home, after Louise's death, discussing ways we might remember her, Sweet Louise was born - an organisation that would help women to live with secondary breast cancer, to give them information to make that easier, support them when needed and to make it possible for them to have some treats to enjoy and perhaps give special memories to them and their families.

To my knowledge this organisation is unique. We have been fortunate to have many extraordinarily dedicated staff, an especially talented board of trustees and some very generous supporters. We have far exceeded our initial dreams and plans, but there is always more to do.

I hope our current and future members will find this booklet helpful in living every day to the full and continue to inspire us all to do more.

**From Dr Vernon Harvey**

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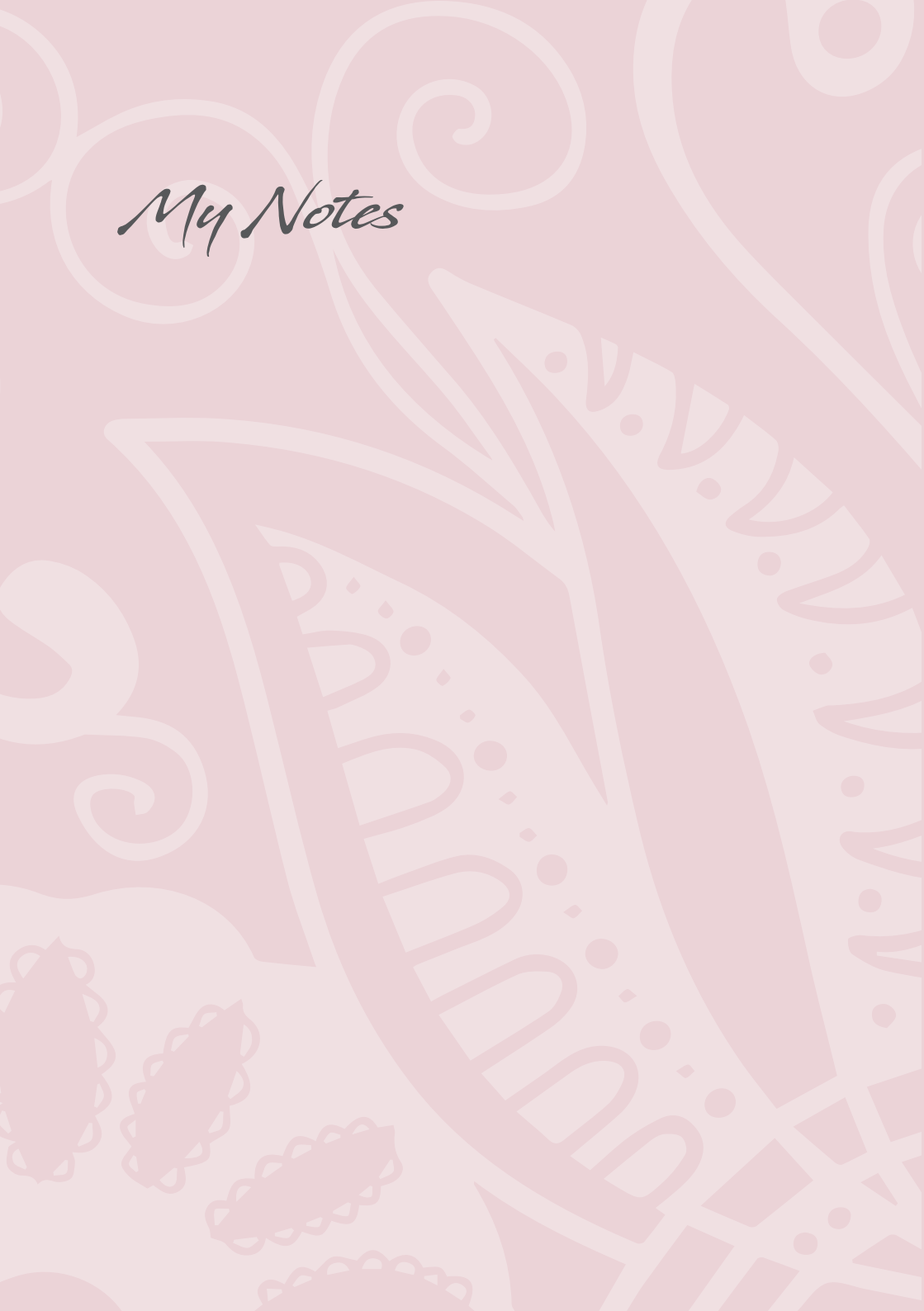


# ***How Sweet Louise Can Help***

*In this picture Harriet nestles behind her husband Grant on their large touring bike, clinging tightly with her eyes closed, thinking of all the road trips they took together through New Zealand. She wasn't well when these shots were taken, and like their road trips together, she was spending a lot of time sheltering behind Grant. The road ahead looked tough and she wasn't quite ready to turn round that bend.*



# *My Notes*





# ***What is Sweet Louise?***

Sweet Louise was launched in 2006 as a unique charitable organisation providing support and services for New Zealanders living with secondary (also known as 'advanced' or 'metastatic') breast cancer. Membership to Sweet Louise is free and open to all women and men living in New Zealand who have received a diagnosis of secondary breast cancer.

Sweet Louise was inspired by the life of Louise Perkins who lived with metastatic breast cancer for ten years, until the age of 39. Louise embraced life to the fullest. She lived with absolute positivity and went about life with cancer as part of living, rather than as a main focus of her life.

**Louise had some *Tips for Life* and we'd like to share them with you:**

- ***Go to the party***
- ***It's not about how you look, it's about how you are***
- ***Five fruit and veg***
- ***Buy the present for the person***
- ***Touch, listen, trust***
- ***Positive visions***
- ***Think of the good in people***
- ***Is there something sweet?***
- ***Love the children***
- ***Don't procrastinate, do it!***
- ***Tell me how you feel, not just what the facts are***

***But most importantly, LOVE***

Our purpose is to help improve the quality of life for women and men with metastatic breast cancer. We achieve this by providing a comprehensive range of support, services and therapies designed to enhance well-being. All services are approved by our Medical Advisor.

Locally based Support Coordinators with a health professional background and/or experience in oncology/palliative care, support members through home visits, email communication, telephone support and Member Meetings (in some locations).

## ***What can we offer you?***

Sweet Louise offers its members access to a range of services that complement existing medical and community support services.

### **We provide:**

- An annual allocation of vouchers worth \$500 to spend on our range of complementary and practical services.
- Monthly Member Meetings (in some locations) offering peer support, inclusive activities and interesting speakers presenting on relevant topics.
- An informative website.
- A wide range of information resources, both electronic and printed.
- Referrals to, and collaboration with, community organisations supporting families experiencing cancer.

Services are grouped under categories, as follows (please check with the Support Coordinators for the latest Service Directory as some services may change or visit: **Our Services** on the website **[www.sweetlouise.co.nz](http://www.sweetlouise.co.nz)**.

***“ It is hard to place a value on Sweet Louise and the fellowship, support and companionship this organisation offers to women with metastatic breast cancer. ”***

Aashi





## ***Sweet Louise Mind***

- Counselling and emotional support
- Creative therapies
- Positive mind techniques



## ***Sweet Louise Body***

- Acupuncture
- Body wear
- Exercise
- Footcare
- Haircuts, wigs and hats
- Hydrotherapy
- Looking great
- Lymphoedema therapy
- Massage
- Photography
- Reflexology
- Reiki
- Tai Chi



## ***Sweet Louise Helpers***

- Baking
- Celebrant Services
- Handyman services/help around the home
- Home cleaning
- Lawns and gardens
- Meals
- Personal home care
- Transport



# *My Notes*

**“ It was a shock to receive the news.  
Cancer returning had never entered my mind and  
it was the last thing I expected. ”**

Shirl



# **What You Can Do Right Now**

**"Living with cancer has its ups and downs but it's the family, friends and support that helps me get by day by day, and keeps me going. Without the support I've had I don't think I would be here today."**

Tina

# *My Notes*

“ I feel as if I’m walking on a tightrope, way above the trees and the view from up here is just lovely! I’m cramming in everything I can think of that I can do. I do get the speed wobbles up here and sometimes I’m clinging on by my fingernails and I know that one day I will fall but I’ve stayed up here longer than they thought I would. ”

Gabrielle

# ***A diagnosis of secondary breast cancer***

A diagnosis of secondary (also known as 'advanced' or 'metastatic') breast cancer was the last thing you expected, or, after a diagnosis of primary cancer, you may have held a fear that cancer would return, and now it has.

There are some things you know for sure and other things you are not so sure of. Whether fact, fiction or just 'don't know', you will be responding with almost every emotion and feeling you have: anger, fear, sadness, loneliness, humour (yes, that too!), despair, anxiety, apprehension and more. You may even feel relief to finally know, especially if you had suspected something was wrong.

It's okay to feel all of these things and more. People will say, 'Try to think positive!' but you can 'be' whatever you like, and 'think' and 'feel' whatever you want.

The main thing at this stage is to take some time to process what has happened, let the overwhelming emotions run their course and then make some decisions about the way forward: treatment options, how to tell family and friends, what to do about work. The news you've received will have an impact on every part of your life. Don't feel rushed because this is a time to let your feelings out, throw rocks at the garden fence ... and then regain some equilibrium. We hope our information booklet will help.

In this first section, we discuss some key questions you may have in your mind and provide some suggestions. Throughout the booklet you will find quotes from our Sweet Louise Members who share their thoughts and feelings in the hopes their words will resonate with you at this difficult time.

***“ Really, it blew my life apart. If people say they feel devastated when first diagnosed with breast cancer, they feel doubly shattered when they are told the cancer has metastasised. ”***

Jenny



# ***What is secondary breast cancer?***

## ***What is cancer?***

Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues of our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair. Cells receive signals from the body telling them when to divide and grow and when to stop growing. When a cell is no longer needed or can't be repaired, it gets a signal to stop working and die.

Cancer develops when the normal workings of a cell go wrong and the cell becomes abnormal. The abnormal cell keeps dividing making more and more abnormal cells. These eventually form a lump (tumour). Not all lumps are cancerous. Doctors can tell if a lump is cancerous by removing a small sample of tissue or cells from it. This is called a biopsy. The doctors examine the sample under a microscope to look for cancer cells.

A lump that is not cancerous (**benign**) may grow but cannot spread to anywhere else in the body. It usually only causes problems if it puts pressure on nearby organs.

A lump that is cancer (**malignant**) can grow into nearby tissue. Sometimes, cancer cells spread from where the cancer first started (the primary site) to other parts of the body. They can travel through the blood or lymphatic system when the cells reach another part of the body, they may begin to grow and form another tumour. This is called a secondary cancer or a **metastasis**.

## ***Secondary breast cancer***

Secondary breast cancer happens when cancer cells spread from the cancer in the breast to other parts of the body. The cancer that starts in the breast is called the primary breast cancer. In many women, primary breast cancer never comes back after treatment. But sometimes breast cancer cells spread through the bloodstream or lymphatic system to other parts of the body.

The lymphatic system helps us to protect us from infection and disease. It's made up of fine tubes that connect to groups of lymph nodes (sometimes called glands) throughout the body.

Breast cancer cells that have spread may eventually form another cancer or tumour. This is called a secondary breast cancer or a metastasis. Occasionally, women are diagnosed with secondary cancer at the same time as the primary breast cancer is found.

The secondary cancer is made up of breast cancer cells. Doctors treat it with the same drugs used to treat breast cancer. So a secondary breast cancer in the lung is treated as breast cancer, not as a lung cancer.

The most common places breast cancer can spread to are the bones, lungs, liver or brain. This does not mean that secondary breast cancer will spread to all of these places.

Less commonly, breast cancer can spread to other parts of the body, such as the skin, bone marrow, ovaries or lining of the abdomen (peritoneum).



## **Local and regional recurrence**

Breast cancer that comes back in the previously treated breast or in the operation scar is called a **local recurrence**.

If the cancer comes back in the lymph nodes in the armpit, close to the breast bone, or in the lower neck it's called a **regional recurrence**.

When cancer cells block the lymph nodes in the armpit, fluid can build up in the arm causing swelling known as lymphoedema.

Even though these recurrences are not in the body's organs, your doctor usually recommends tests to check the cancer has not spread further.

If the cancer has not spread anywhere else in the body, you will have surgery if possible, or radiotherapy to the area, or chemotherapy. Your treatment will depend on the previous treatments you had for primary breast cancer.

## **Symptoms**

The symptoms of secondary breast cancer depend on where in the body the cancer has spread.

You may have some general symptoms. These can include feeling much more tired than usual, losing your appetite or feeling generally unwell for no obvious reason.

The symptoms we mention here can be caused by other conditions. But if you have any of them, see your doctor or breast care nurse. Always tell them if you develop new symptoms, especially if they last more than a week or two.

Over the next few pages, we list some possible symptoms of secondary breast cancer in different parts of the body.

## ***The bones***

The most common symptom is a nagging ache in the bone. It may be painful when you move around or make it difficult to sleep. Aches and pains are common and can be caused by different things, such as hormonal therapy or menopause. But it's important to tell your doctor if your symptoms continue.

If the cancer has spread to the bones, it can often be controlled for many years with different treatments.

Some other bone problems may develop. These are not common when you have just been diagnosed, but it's important to know about them.

## ***Too much calcium in the blood***

If the cancer damages the bone, it can cause calcium (a mineral stored in bones) to be released into the blood. A high level of calcium in the blood (hypercalcaemia) can cause symptoms such as feeling tired, sick or thirsty, passing more urine, constipation or feeling confused. Doctors can see that calcium levels are rising on a blood test before symptoms develop. They can treat this with drugs.

## ***A break in the bone***

If the cancer gradually damages the bone, it may become weaker. Occasionally a very weak bone can break (fracture). However, treatment is usually started before a bone is weak enough to break.

## ***Pressure on the spinal cord***

If the cancer has spread to the bones of the spine, it may cause pressure on the spinal cord.

### **The symptoms may include:**

- Unexplained pain in the back, around the chest, neck or down the arm.
- Numbness or pins and needles in toes, fingers or buttocks; unsteadiness or difficulty walking.
- Problems with bladder or bowel control.

It is very important to let your cancer doctor or nurse know immediately if you have any of these symptoms. Doctors can usually treat spinal cord compression successfully when it is diagnosed quickly.

### ***The lungs***

The first symptoms may be a cough that does not get better or feeling breathless.

If cancer cells settle in the tissues that cover the lungs (called the pleura), it can lead to irritation. This causes fluid to build up and press on the lungs, making you breathless. This is called a pleural effusion. Your doctor can drain the fluid away to make your breathing easier.

Doctors use different treatments to treat and manage breathlessness.

### ***The liver***

Some women may have discomfort or pain in the right side of the tummy (abdomen) under the ribs around the liver. Other symptoms can include feeling sick, losing your appetite, or feeling very tired and generally unwell.

Occasionally, secondary breast cancer in the liver causes a build-up of bile in the blood causing jaundice. This makes the skin and whites of the eyes yellow and your skin feels itchy.

You usually have chemotherapy to improve these symptoms.

### ***The brain***

A secondary cancer in the brain may cause headaches and feeling or being sick. These symptoms are caused by increased pressure in the brain and they may be worse first thing in the morning.

Other symptoms will depend on the part of the brain that's affected. They can include weakness or numbness in an arm or a leg, dizziness, loss of balance, or changes in mood or personality. Some women may have seizures (fits).

It is natural to feel worried about a cancer that affects the brain, but treatments can usually control the symptoms quickly.

Doctors give radiotherapy to the head and drugs called steroids to improve the symptoms.

### ***The meninges***

Occasionally breast cancer cells may spread to the tissue called the meninges that covers the brain and spinal cord. Doctors call this meningeal metastases or carcinomatous meningitis. It causes symptoms similar to a secondary cancer in the brain.

*“ There are so many knowledgeable people out there in the Sweet Louise community. People who actually understand how lousy a situation you are actually in, and how hard it is sometimes to get out into the world and live. ”*

Nicola



*Nicola and Ryan*

# ***Diagnosing secondary breast cancer***

## ***How secondary breast cancer is diagnosed***

Some women see their GP with a new symptom. Your GP may arrange some tests or refer you directly to your cancer doctor (oncologist).

Sometimes women don't have any obvious symptoms. Their doctor may notice something at a routine appointment that needs to be checked further. Tests then show there is a secondary cancer.

Occasionally, women are diagnosed with secondary cancer at the same time as the primary breast cancer is found.

## ***Tests***

Your oncologist will examine you and ask questions about your symptoms and general health. You will usually also see a specialist breast nurse who will give you information and support.

Your doctor and nurse will explain which tests you need. This will depend on your symptoms. You will usually have some of the tests listed over the next few pages.

## ***Blood tests***

Blood tests cannot diagnose secondary breast cancer but they may show that you need further tests.

### **They can be used to:**

- Check how well the liver and kidneys are working.
- Check the level of calcium in the blood .
- Measure the number of blood cells to show how well the bone marrow (where the blood cells are made) is working.
- Measure tumour markers – some cancers produce proteins or tumour markers that may be raised – but the results aren't always reliable so it's not always helpful to do this.



# X-rays

## Bones

You may have an x-ray to check a painful area in your bones. It may not be able to detect small areas of secondary tumours. You will usually have a bone scan to confirm the diagnosis.

## Bone scan

A tiny amount of a mildly radioactive substance is injected into a vein, usually in the arm, and travels around the body in the bloodstream. Abnormal areas of bone absorb more radioactivity than normal bone and show up on a scanner.

The scan pictures are taken 2-3 hours after the injection. Bone scans can't always tell whether an abnormal area is due to cancer or other conditions, such as arthritis. Sometimes you may need more detailed scans, such as CT or MRI scans.

## Lungs

A chest x-ray can help to see if there is secondary breast cancer in the lungs. It can also see any build-up of fluid between the membranes on the outside of the lungs (the pleura). You'll also usually have a CT scan.

## Liver ultrasound

This uses soundwaves to build up a picture of the liver. It's painless and only takes a few minutes. The person doing the ultrasound spreads a gel onto your tummy (abdomen). They pass a small device like a microphone, which produces soundwaves, over the area. The soundwaves are converted into a picture by a computer. You may have a CT scan of the liver rather than an ultrasound.

**“ I felt so scared and lost when I received that diagnosis. I thought my life was over and had no idea how to cope. It's a challenge to keep on top of my treatment, and my life beyond cancer. I have learned to keep notes on appointments, get copies of my scans and ask about all the treatments that are available to me. ”**

Heather

## **CT (computerised tomography) scan**

A CT scan takes a series of x-rays, which build up a three-dimensional picture of the inside of the body. The scan takes 10-30 minutes and is painless. It uses a small amount of radiation, which is very unlikely to harm you and will not harm anyone you come into contact with. You will be asked not to eat or drink for at least four hours before the scan.

You may be given a drink or injection of a dye, which allows particular areas to be seen more clearly. This may make you feel hot all over for a few minutes. It's important to let your doctor know if you are allergic to iodine or have asthma, because you could have a more serious reaction to the injection.

You'll probably be able to go home as soon as the scan is over.

## **PET (positron emission tomography) /CT scan**

This is a combination of a CT scan, which takes a series of x-rays to build up a three-dimensional picture, and a positron emission tomography (PET) scan. A PET scan uses low-dose radiation to measure the activity of cells in different parts of the body. PET/CT scans give more detailed information about the part of the body being scanned. You may have to travel to a specialist centre to have one. You can't eat for six hours before the scan, although you may be able to drink.

A mildly radioactive substance is injected into a vein, usually in your arm. The radiation dose used is very small. The scan is done after at least an hour's wait. It usually takes 30-90 minutes. You should be able to go home after the scan.

## **MRI (magnetic resonance imaging) scan**

This test uses magnetism to build up a detailed picture of areas of your body. The scanner is a powerful magnet, so you may be asked to complete and sign a checklist to make sure it's safe for you. The checklist asks about any metal implants you may have, such as a pacemaker, surgical clips or bone pins. You should also tell your doctor if you've ever worked with metal or in the metal industry as very tiny fragments of metal can sometimes lodge in the body.

If you do have any metal in your body, it's likely that you won't be able to have an MRI scan. In this situation, another type of scan can be used. Before the scan, you'll be asked to remove any metal belongings including jewellery.

Some people are given an injection of dye into a vein in the arm, which doesn't usually cause discomfort. This is called a contrast medium and help the images from the scan to show up more clearly.

During the test, you'll lie very still on a couch inside a long cylinder (tube) for about 30 minutes. It's painless but can be slightly uncomfortable, and some people feel a bit claustrophobic. It's also noisy, but you'll be given earplugs or headphones. You can hear, and speak to, the person operating the scanner.

## **Biopsy**

Some women have a piece of tissue removed (biopsy) from the secondary cancer to confirm the diagnosis.

The biopsy will also help to find out whether the cancer cells have certain receptors (ER or HER2). The secondary cancer may not be identical to the primary breast cancer.

You usually have the biopsy under a local anaesthetic as an outpatient. The doctor uses an ultrasound to help them guide the needle to the right place. Sometimes it may not be possible to do a biopsy if the cancer is in a difficult area to reach.

After the biopsy, the area may feel a bit uncomfortable for a couple of days. You can take regular painkillers to help with this until the pain goes away.

## **Waiting for test results**

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results of your tests to be ready. You may find it helpful to talk with your partner, your family or a close friend. Your specialist nurse or your Sweet Louise support coordinator can also provide support.

# ***Staging and receptors***

## ***Staging***

The stage of a cancer describes its size and if it has spread from where it started. This information affects the decisions you and your doctor make about your treatment. Doctors often stage breast cancer using a system that divides it into four number stages.

Secondary breast cancer is stage 4. This is when the cancer has spread to other parts of the body such as the bones, liver or lungs.

Doctors sometimes call secondary breast cancer metastatic breast cancer.

## ***Receptors***

Breast cancer cells often have receptors (proteins) that hormones or other signals can attach to and encourage the cells to grow.

A pathologist does tests on the cancer cells to find out whether receptors are present and what type they are. The results help you and your doctor to decide on the most effective treatment for you.

You will usually have had tests for HER2 and hormone receptors done when you were first diagnosed with breast cancer.

You may have a biopsy taken from the secondary cancer to re-check the hormone and HER2 receptors. This is because they may not be identical to the primary cancer. Your cancer doctor will explain more about this.

If you haven't been treated for breast cancer before, your doctor will take a biopsy from the secondary cancer. If this is not possible, they will take a biopsy from the primary cancer.

## ***Hormone receptors***

Some cancers have receptors for the hormones oestrogen and progesterone. Hormones act as chemical messengers and influence how cells grow and what they do.

Breast cancer that has oestrogen receptors is called oestrogen receptor-positive or ER-positive. ER is used because the American spelling of oestrogen is estrogen.

ER-positive breast cancer usually responds well to treatment with hormonal therapies.

Breast cancer that does not have oestrogen receptors is known as ER-negative.



## ***Protein receptors***

Some cancers have receptors for a protein called HER2 or human epidermal growth factor 2. Breast cancers with high levels of HER2 are called HER2-positive. Targeted therapy drugs such as trastuzumab (Herceptin®) are helpful treatments.

Women diagnosed with breast cancer now always have the cancer cells tested for HER2 receptors. If you were diagnosed with primary breast cancer a long time ago, you may not have had this done. Your doctor will try, if possible, to take a biopsy from the secondary cancer or use cells from previous biopsies or surgery for testing.

## ***Am I to blame?***

It's easy to think that maybe something you did - or failed to do - caused the diagnosis of secondary breast cancer. Unfortunately, some breast cancers will progress to secondary stage, irrespective of lifestyle changes that we make and treatments we have received for early stage. So no, you are not to blame.

***“ I ... was diagnosed with secondary breast cancer in the liver. You always know in the back of your mind that one day you're not going to be here but to be told that for sure is a completely different ball game.***

***It came as a shock. None of us know how long we've got ... but knowing it's going to happen is the scary thing. The oncologist didn't put a time frame on it. He just said, 'I can give you a rough average but we don't know.' ”***

Elizabeth



## ***Will I die?***

After receiving a diagnosis of secondary breast cancer, death may be one of the first things you think of and ask about. The reality that the cancer cannot be cured is hard to accept. The information you are given by your specialist may be frustratingly inconclusive, especially at this time, and it may be difficult for him or her to determine how long you will live. Coming to terms with the uncertainty of the diagnosis can be difficult, so:

- Talking it through with someone who has insight can be helpful - your medical team, your Sweet Louise Support Coordinator, other women living with secondary breast cancer.
- Letting some time go by, allowing the information to settle, can help make the situation less overwhelming.
- Remember there is still a lot of life to be lived. Start living day to day, enjoying the moment. Living with advanced cancer will be a different life, not a journey towards death.
- Be assured that there are many treatment options available that can control or slow the growth of the cancer and relieve symptoms. A treatment regime will be planned for you and the priority will always be to make you as comfortable as possible - both physically and emotionally.





## How long will I live?

It's natural to want to know what will happen in the future and living with uncertainty can cause anxiety. Suddenly you're unable to make plans. There's a loss of control over your own destiny. This is stressful and when you ask your medical team how much time you have, they will probably reply, "I can give you my best guess."

An answer like this might seem unhelpful, but your medical team may be unable to give you a better one at this time and will be reluctant to provide information that cannot be substantiated by facts. Perhaps view this particular question as the basis for ongoing discussions, because as time goes on, and situations change, your desire to talk about it may change too.

Life expectancy can be affected by a number of things. The effectiveness of the treatment, the speed of cancer growth and your general health overall are all factors that may determine this. However, there may also be times when you need to know as accurately as possible - perhaps you are making plans for the future - so let your specialist know and ask them to be as specific as they can.

It's OK to not ask this question because some people prefer not to know. The subject may come up and you can choose to discuss it, or not. It is always your choice.

- Try setting some short term goals for yourself, some that are small and easy to achieve.
- Finding out as much as you can about your cancer can help with longer term plans - don't be afraid to ask lots of questions. Take a list of questions to discuss with your specialist or medical team.
- Information is empowering.
- Take a loved one or friend with you to appointments.

**“ My oncologist says it’s hard to know how long I’ll be here so I frame my questions in such a way that I get the information I need. I want to make plans, get things in order so I need to know. ”**

Jenny

## What do I do?

You've probably heard it before ... but taking time to reach a point of understanding what has happened so you can process information, ask questions and find a way forward can be one of the best things you can do. Discussing your prognosis with your medical team provides valuable information, but can create anxiety and uncertainty because they will not be able to tell you exactly how your cancer will go. Gathering the facts, asking questions and making informed decisions can offer you back some control, so take your time.

*In a beautiful Catholic Church in Lower Hutt, twice a week, you'll find Mary Margaret singing in a choir. Like most Sweet Louise Members, Mary Margaret receives powerful support from family, friends and the folks at Sweet Louise.*

*But she has a special place in her heart for the time she spends with her choir friends. There Mary Margaret, from Canada, finds the harmony she needs for her journey.*



# How do I carry on?

Faith and hope can carry us through difficult times and a diagnosis of incurable cancer can make us search for strength within ourselves. We all possess an incredible depth of courage and hope and these two qualities can manifest themselves in the simplest of ways. We may hope for a good afternoon in the garden. Our courage may inspire us to try something a bit daring that we've always wanted to do.

Sometimes our lives telescope inwards and we hope from minute to minute, hour to hour, day to day. It's all OK. Living in the moment can be comforting, reassuring and rich.

## Here are some tips that may help during this time:

- Gather information about advanced breast cancer from reputable sources - sometimes the more you know, the more control you have and the better you feel. Beware of information on the internet - some is reputable and clinically proven, some is not. Discuss your research findings with your medical team before taking action. See Books and Websites on page 121.
- Talk to someone who has 'been there too' - Sweet Louise can help.
- Tell those close to you what you need and how they can help - accept offers of assistance.
- Take some 'time out' for you - we need a breather every now and then, so take yourself off to do something you enjoy.
- Let your feelings out - keep a journal, make a scrapbook, listen to music, dance!
- Don't be afraid to say 'no thank you' if you don't feel like doing something - people will understand.
- Practice 'being in the moment' to give your thoughts and emotions a break - sit in the sun, look at the flowers, notice the sights, sounds and sensations of nature all around you.

***“I have a mantra these days: forget about yesterday, don't worry about tomorrow, and enjoy today. I wish I'd been doing that since the age of 21.”***

Jenny

## ***The emotional impact***

A diagnosis of serious illness can bring about confusion and collision of just about every emotion and feeling that we have - and this can happen not only for us, but for those around us too.

If there is one reassuring thing we can say right now, it would be, 'this is completely normal.'

Try to let the emotions 'do their thing', let them run their course. If sadness, depression or fear hang about for too long, it may be an idea to speak with someone about it, because our negative thoughts can affect our overall health and wellbeing. A trained counsellor, a Sweet Louise Support Coordinator or perhaps your GP could be three choices. Don't hesitate to ask for help. Putting your hand up is not a sign of weakness. We all need help from time to time.

A diagnosis of cancer affects our relationships with partners, family and friends. It can mean changes in our professional occupations, financial situations and can impact our physical abilities too. Choosing to ignore feelings and realities can create even more problems for everyone so in this section we feature some ideas and suggestions that may help you, and those close to you.

- Worrying 24/7 can be exhausting - try setting aside an hour each day as 'worry time'. Focusing on your worries by 'compartmentalising' them can help keep you calm for the rest of the day.
- Try to see secondary breast cancer as a 'chronic illness' requiring treatment, not a 'terminal disease'.

***“ It’s our story. It’s who we are and it’s why we’re there so let’s talk about it. That was part of the discussions at the Sweet Louise meeting and I liked that. I learned a lot and felt reassured when I left because I knew there were other women with bone cancer. I’d never met any before and if it wasn’t for Sweet Louise, I wouldn’t have had the chance. ”***

Jaime

- Think about joining a support group. Peer support (from women who have 'been there too') is now highly recommended by medical professionals as an effective way of coping with a cancer diagnosis. Sweet Louise offers regular Member Meetings which provide opportunities for you to meet other women in similar situations. The reassurance, comfort and information received from other women can be of great value. If a group situation is not for you at this time (but perhaps later) Sweet Louise offers a toll free line on **0800 11 22 77** where you can speak to one of the Support Coordinators. They may also be able to put you in touch with another Member who will speak with you over the telephone.
- Consider joining an online group. Metavivors NZ is a small but thriving and growing facebook group for those living with secondary breast cancer. It offers opportunity to share experiences, discuss issues and decide where advocacy is needed. The group is private and members can ask to join or be invited to join by a member.  
To join please contact BCAC: **bcac@breastcancer.org.nz**
- We all have a remarkable capacity for hope. This will not leave you.

Sweet Louise Service Providers offer a range of relaxing therapies which may help during this difficult time; for example, massage, reflexology and reiki. Attending Member Meetings can provide opportunities to talk to others who have 'been there too' and understand how you feel.

**“It's hard on partners. My husband is a tower of strength. I never see him weaken which is good for me but I know partners need to work through a lot too.”**

Jaime





## ***Your partner***

The stresses of your diagnosis, the physical effects of treatments and an uncertain future can put considerable strain on the relationship with your partner. Their stress levels can be as high as yours.

- Their paramount fear is that of loss and sometimes professional help is needed - don't hesitate to seek it.
- A diagnosis of serious illness can change the role of your partner from spouse to caregiver and there are many feelings that go along with that.
- Sometimes they can perceive their support as being poor or ineffective.
- Their needs for information can differ from yours and they may feel these are not being met.
- There is the notion that reassurance can be helpful ("It's all going to be all right.") but sometimes it isn't and their failed attempts to reassure can make them feel powerless, helpless, frustrated.
- Your cancer is something they simply cannot fix.
- Some may cope with the diagnosis through avoidance, demand and withdrawal (e.g. "I want you to do this for me ... but I know you won't ...") but this can be counterproductive - so tell your partner, family, and friends what you need as they will respond better to what you want, and acknowledge that they are having a hard time too.

## ***What you can do:***

- **Open and honest communication - share the ups and downs and take the journey together.**
- Sometimes all you need is for your partner to listen, and vice versa.
- Say what it is you need - your partner can't always read your mind!
- Encourage your partner to think about his or her needs as well - work together to find solutions and support.
- Both of you may need 'time out' from each other sometimes - recognise this and allow for it.
- Mutual, constructive conversation and the provision of information specific to the need can help. When conversation is too difficult, you could try writing down your concerns/issues as a list, or in a letter to your partner.
- Seek advice and help if/when you need it - from a friend, relative, or counsellor - someone who is well outside of your situation. There is no shame in asking for help.
- Enjoy some special times together - plan these and make them a priority. Take a weekend break or visit favourite places that hold precious memories for you both.
- Sweet Louise offers a Support Group for Partners in some parts of New Zealand - call us on **0800 11 22 77** for information about a group in your area.



## ***Sex and intimacy***

Just because you have cancer doesn't mean you need to stop having sex. Sex will not make your cancer worse and, in fact, a sexually loving relationship can provide comfort, reassurance and support.

Cancer may affect your desire for sex sometimes. You might find you cannot - or do not want to - have sex as often as you did before your diagnosis. The symptoms of the cancer and side effects of treatment may cause physical discomforts during sex (for example, pain and vaginal dryness) and general worries, fatigue and anxieties can lower our enthusiasm for sex. Your partner may be concerned about hurting you during sex or have general concerns about the effect sex may have on your illness.

There are other ways to share love and intimacy. Experiencing pleasure through touching, stroking, kissing and cuddling can bring enjoyment and satisfaction, as can massage. It is very important to speak openly and honestly with your partner so your mutual needs are met and misunderstandings can be avoided.



*Cherie and Martin*

If you are having sexual problems, do discuss this with someone from your medical team (perhaps your Oncology Nurse). They can advise you or refer you and/or your partner to a specialist counsellor who can help.

### **Here are some other things to think about:**

- Avoid creating barriers by speaking to your partner with openness and honesty.
- Try 're-writing the script' - think about what your sexual relationship was like before and how you can change certain things to improve it now.
- Think of ways to 're-light the pilot light' - create anticipation by imagining sex before it happens and try other ways of being romantic and intimate with each other.
- Be an 'active listener' - listen to your partner, discuss needs, preferences, frustrations, what works and what doesn't.
- Think about the non-sexual aspects of your relationship. Discuss this with your partner outside of the bedroom, maybe at a favourite place you both enjoy.
- Vaginal dryness is a side effect of treatments. Loss of lubrication can cause difficulties during intercourse including delayed arousal, pain and discomfort (if experiencing pain, ensure that this is not due to infection or vaginal atrophy, conditions that would require medical treatment). Use of water-based or silicone-based lubricants can help, such as Sylk, Sliquid and Pjur. A product that will stay moist for some time is best and avoid oils (such as baby oil) as they can cause vaginal inflammation. Become knowledgeable about the problem, discuss with your partner, try lubricants and find one that suits you.
- Regular moisturising of the vulva and vagina (and using a water-based lubricant during sex) can become a helpful routine.
- If using condoms, use non-latex varieties as latex can irritate the vaginal area.
- Pelvic floor exercises may help.
- Urinary and bladder control can be affected by menopause (natural or brought on by chemotherapy treatments) and bladder infections can occur after sex. See your GP.

## ***If you are single***

The thought of beginning a new relationship may seem a little daunting. Thinking about when and how to tell a new partner about your breast cancer, and living with a future that is uncertain, can seem difficult. Most people will know someone who has been affected by breast cancer and so will have some understanding of its challenges. Try reversing the roles - how would you feel if your new partner told you they had breast cancer?

Having sex again may make you feel a bit anxious - and this is normal. Beforehand, think about what would make you comfortable. Maybe it's creating a romantic atmosphere or wearing clothing/lingerie that makes you feel attractive and confident. If you are experiencing pain in parts of your body, try positions that are comfortable for you and use cushions/pillows to take pressure away from those sore areas.

Some women prefer to tell a new partner up front, others wait until they feel more confident and have trust in that person. There is no right or wrong time - go with whatever you feel is best for you. If you are having difficulties, a counsellor or psychologist can help you work through it. Most divisions of the Cancer Society of New Zealand offer free counselling for cancer patients.



# ***Telling your children and grandchildren***

A diagnosis can be particularly distressing for children and how they understand and appraise the situation depends on their age and maturity. Telling them isn't easy and their response can be determined not so much by the illness but more by how you present the information and how well prepared they feel. As a parent, your emotions will be running high regarding your children - fear, anger, denial, anxiety, sadness. Choose the time for family discussion carefully, a time when you can sit without interruption and you feel calm enough to speak from a place of truth, openness and hope, creating a firm foundation upon which to build as you begin the journey together.

**There is no 'right or wrong' way to speak with your children. Here are some ideas that may help:**

- How and what you tell your children will depend on their age and how much they can understand. Picking the right time to tell them is important too - perhaps when you, your partner, relatives or close friends can be together. The children will be reassured by the supportive presence of other adults they can share their feelings with.
- The most pervasive emotion for children is anxiety - what will happen to you and so what will happen to them. Be sure your children know they will be looked after, no matter what.
- Be honest. Tell them that your cancer has come back or spread. Even very young children will sense when something is seriously wrong so explain the situation and reassure them.
- Younger children may think the cancer is their fault, believing that something they did caused this to happen to you (for example, they may feel guilty because they did something naughty or disobeyed an instruction and your cancer was the outcome). Reassure them that no one is to blame, least of all them.

- Try not to pretend that everything is fine. Children are very perceptive. They will know something isn't right and may keep their worries to themselves, causing isolation and a feeling that they cannot tell you how sad or upset they are.
- An overload of medical detail isn't necessary - keep it simple. Explain your illness and describe the treatment you will be having and how it will help.
- Let your children know how they may be affected by your treatment. There may be days when you are too unwell to join in their activities and you may need some extra help around the house. Older children may need to take on additional domestic duties which they may perceive as 'a disruption' to their lives so explaining the reasons why, in detail, can help.
- If you go into hospital, let your children know when they can visit you and tell them they can call, text or email you.
- Talk openly about how you are feeling because this may help them express their feelings too.
- Children of any age may worry that you are going to die. If your cancer is likely to be controlled for a long time, it's important to say so. If the cancer is more advanced, it is helpful to gently prepare the children for your death. This can be a very difficult thing to do so seek help and support if you need to.
- Your local division of the Cancer Society will have books and resources specifically for children that may be helpful.
- Most divisions of the Cancer Society offer free counselling for cancer patients and their families.

Teenagers tend to experience the greatest impact. They are seeking independence, dealing with a range of emotional and physical issues of their own ... and 'now this has happened.' They feel a greater stress, especially when asked to take on more tasks around the home. There is the stigma of a mother who 'isn't cool' and this can cause embarrassment, anger, resentment. Their reactions to the situation can, in some cases, cause long term behavioural problems and timely professional help should be sought. Here are some tips that may help:

- In general, adolescents can be supported through the open provision of information and opportunities to talk about what is happening.
- If they are finding it too hard to talk to you, encourage them to talk to someone close who can support them - a relative or friend.
- They still need structure and routine so ensure that rules (and consequences if they are broken) are still in place.
- Talk, negotiate tasks, encourage participation in sport and social activities (as usual), reassure them that none of this is their fault and provide relevant information in manageable stages.
- Don't: keep secrets, let go of rules and routines, give orders or expect children to stay home all the time.
- Do: let others help out with the children (e.g. take them to sports practice - letting others show their love is a gift you can give), allow the children to talk through difficult things, and let the school know.
- Sweet Louise can refer children and young people to organisations that can help at this stage in their lives and yours.  
Call us on **0800 11 22 77** for information.

### **Some reassuring things you and your partner can say may be:**

- We will always take care of you, no matter what happens.
- We will answer all of your questions so ask us any time.
- If you're afraid, lonely or sad, talk to us - we will deal with this as a family.
- We will try to keep life as normal as possible for you.
- The medical team are doing their very best.

## ***Telling relatives and friends***

We often hear the words, 'It'll be good when things get back to normal with you' because those around us want a return to life as they knew it. We wish for this too ... but life 'as we knew it' has changed and it can take some time for us, family and friends to find a way forward.

People close to you will want to help but aren't sure how. Sometimes they may say things that are hurtful or puzzling and these are often their attempts to cope with a situation that is frightening and new for them. There may be some friends or family members who cannot cope and they might back away from you despite your attempts to stay in touch. Rejection like this can be painful and difficult to accept but always remember that it is not your fault. They are behaving in this way due to their own difficulties in dealing with your illness.

You may feel let down or disappointed by the responses of people who may see you as coping and capable when, in fact, you are struggling. If you think this is happening, ask yourself the question, 'Would you offer to help you?' Sometimes making a self-effacing comment can help to ease into a discussion with someone, for example, 'Maybe I withdrew and you didn't know what to do.'

*Susan and Nadine*



### Here are some things to think about:

- Living with advanced breast cancer has been likened to 'living in the shadow lands' and people may feel obliged to tell you every negative story they know. Remember that whilst this type of script may not be that great, you are in the director's chair and can take the lead in conversations.
- We're often told to 'put on a happy face' and 'be positive.' Is that for us ... or for them? Humour can help us to bear the unbearable and talking about it will not make it any worse than it already is but 'being positive' for others can cost us a lot of emotional energy.
- Reflect on your own needs and expectations - there are tears to be shed so let them out and tell people this is what you need to do and it is OK.
- When it comes to 'the battle' with cancer, everyone has an opinion about that and will happily share it with you.
- People need to find reasons for what has happened, so exert some control over the situation - there is pressure put upon you to be grateful that you are still here and have 'won the battle'. We do not owe it to these people to follow their advice or do what they suggest.
- Master the art of declining offers or advice that you don't wish to accept.
- Tell your friends what you need - often they are not sure how to help and by telling them, you give an opportunity for them to really make a difference for you that will make them feel good and useful.

***“ I sense people are sometimes afraid to ask how I am so I let them know I don't mind them asking and even if I'm feeling rotten, I will tell them! I'm quite out there, don't hide things and I'm glad when people call – they can ring any time. ”***

Jenny



# ***Communicating information on your terms***

It's up to you to decide how much information you wish to share, when and with whom. It can be very tiring relaying information to a lot of people so below are some ideas that may be helpful.

- Family, friends and colleagues may be unsure about talking to you and could be leaving it up to you to make the first move. Sometimes a short phone call or sending an email can show them you are willing to keep up contact but tell them as much or as little as you like about your health.
- Tell people what you need as they may not know, whether it's help with some housework or children or just their company over a cup of tea. They will probably welcome the opportunity to help with something they know will make a difference for you.
- Sometimes you may not want to see anyone, just be on your own for a while. Let other people manage this for you - perhaps someone can answer the phone or go to the door and if you're in the hospital, nursing staff can limit visitors. Don't feel obliged to see people if you need time to yourself.
- If you are working, you may need to take some leave time for treatments so speaking with your employer is a good idea. It is possible to work through treatments and many people do. If you are unable to work, making an appointment with Work and Income to discuss your eligibility for a sickness benefit may be helpful. The hospital or Hospice Social Worker can advise you on accessing government benefits. Contact information for community resources are listed in Section 5 of this booklet.
- Many people use email to stay in touch these days - make up a mailing list of relatives and friends and send a group email update.
- Make a 'phone tree' with numbers of those who need to know information and can 'spread the word' should your situation change suddenly.
- Add an 'ICE number' to your mobile and/or home telephone: 'In Case of Emergency please call'.

# *My Notes*

“As long as the treatment is working I hope to stay with it. I’m guided by my oncologist. I trust him and I like him. The first time we met I thought, ‘This is going to be hard going’ and then I realised he has to sum up his patients first and figure out what approach to take. He knows that if he pussyfoots around me I’ll say, ‘Get over yourself! I can cope if I know!’ I can’t cope with the unknown.”

Elizabeth



# **What You Can Consider In The Future**

**"The Sweet Louise conference was a real gift. I met a group of beautiful women, with fighting spirits and infectious energy."**

Sonya

*Sonya, Jayden and Zediah*

# *My Notes*

**“ I said to my oncologist, ‘Okay, how do we fix this?’  
I didn’t think doom and gloom but wanted to know  
what we would do next. I can still see myself saying that  
and I think, ‘Gosh, that was brave of me!’ ”**

Helen

# ***Treatment Options***

There is usually time to think about the options available to you and to discuss them fully with your medical team and those closest to you. Taking this time at the start can help you to make an informed choice about your upcoming treatment and medical care.

## **Some things to consider when making a decision are:**

- The benefit the treatment will offer.
- The effect of treatments on your quality of life.
- Whether the benefit offered will be significant enough to choose that treatment option.

## **So much information will come your way so here are some tips:**

- Record the consultation with your doctor (let them know first - most will have no objection) so you can listen to it at home later.
- Have a family member or friend go with you so they can take notes.
- Prepare a list of questions to take with you so the doctor can provide information about specific things you need to know more about.

## **Questions will often pop into our heads so keep a notebook handy for jotting them down. Here are some questions you might like to ask your doctor:**

- What are my treatment options?
- What are the side effects, both short and long term and will they affect my ability to keep working full or part time?
- How many treatments will I need, how long will they take, and should I have someone bring me and take me home?
- What is the benefit I will receive from the treatments suggested?
- Will I need to arrange some extra help at home (with household chores and caring for the family and pets) and plan a special diet for myself?
- How will these treatments affect my sex life?
- How long before I know if the treatments are working?
- Am I eligible for participation in a clinical trial?

# ***A brief overview of treatment options***

## ***Treatment overview***

The aim of treatment is to control the cancer, help you to live well for longer, and relieve symptoms. You may have different or combined treatments one after the other to keep the cancer under control. In between treatments, women often find they can get on with their day-to-day life.

Your cancer doctor and nurse will involve you in treatment decisions and make sure your preferences are taken into account. They help to support you and, if needed, they can refer you for more specialised help in coping with your emotions.

Newer treatments and different ways of giving existing treatments are being developed. Your cancer doctor may talk to you about taking part in a research trial.

**The treatment you have will depend on different factors, such as:**

- Where the secondary cancer is in your body.
- Whether the cancer is ER-positive or HER2-positive.
- Previous breast cancer treatments you have had and how long ago.
- Your symptoms and general health.

If the cancer is ER-positive, your doctor will talk to you about having hormonal therapy. There are different hormonal drugs and treatments that can be used.

Chemotherapy is often used to treat secondary breast cancer. You may have chemotherapy with a single drug or sometimes with a combination of drugs.

If you have HER2-positive breast cancer, you will usually be given targeted therapy drugs, such as trastuzumab.

Your cancer doctor may give you radiotherapy to relieve pain from a secondary cancer in the bone. You can also have drugs to help strengthen bones.

Radiotherapy can also be used to shrink secondary cancer in the brain or in lymph nodes.

Occasionally, surgery is used to remove a small tumour in the brain or to help strengthen a weak bone.

Your doctor can refer you to a specialist doctor or nurse who is an expert in symptom control at any time during or after treatment. This helps make sure that any difficult symptoms you have are controlled. You can see them in hospital and nurses can visit you in your own home.

If, at some stage, you decide not to have further treatment, they will support you and make sure your symptoms are controlled. Experts in this area are sometimes called palliative care specialists.

## ***Planning your treatment***

In most hospitals, a team of specialists will meet to decide on the best treatment for you. This multidisciplinary team (MDT) may include:

- A cancer doctor (**oncologist**) who specialises in giving cancer treatments.
- A **specialist breast care nurse** who gives information and support.
- A **specialist surgeon** (if needed).
- A doctor or nurse who specialises in controlling symptoms.
- A **radiologist** who analyses x-rays and scans.
- A **pathologist** who advises on the type and extent of the cancer.

It may also include other healthcare professionals, such as a physiotherapist, dietitian, occupational therapist, psychologist, social worker or counsellor.

Your specialist will discuss treatment options with you. Remember to ask questions about anything you don't understand or feel worried about. You can discuss the benefits and disadvantages of different treatments with your specialist doctor or nurse.

## ***The benefits and disadvantages of treatment***

Many people are worried at the idea of having cancer treatments, particularly because of the side effects that can happen. But these can usually be controlled with medicines.

Treatment can be given for different reasons and the possible benefits will depend on your individual situation. Usually treatments for secondary breast cancer can help to keep the cancer under control, relieve the symptoms and help you to live for longer.

However, there may be a time when the treatment has little effect on the cancer and women get treatment side effects without any of the benefits. Making treatment decisions in these circumstances is always difficult, and you may want to talk it over carefully with your cancer doctor, specialist nurse and family. If you decide not to have treatment, you will be given supportive care, with medicines to control any symptoms.

*Kelly and Vernon*





## ***Second opinion***

Your multidisciplinary team (MDT) uses international treatment guidelines to decide the most suitable treatment for you. Even so, you may want another medical opinion. If you feel it will be helpful, you can ask either your specialist or GP to refer you to another specialist for a second opinion. Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information. If you do go for a second opinion, it may be a good idea to take a relative or friend with you, and have a list of questions ready, so that you can make sure your concerns are covered during the discussion.

## ***Giving your consent***

Before you have any treatment, your doctor will explain its aims. They will usually ask you to sign a form saying that you give permission (consent) for the hospital staff to give you the treatment. No medical treatment can be given without your consent, and before you are asked to sign the form you should be given full information about:

- The type and extent of the treatment.
- Its advantages and disadvantages.
- Any significant risks or side effects.
- Any other treatments that may be available.

If you don't understand what you've been told, let the staff know straight away, so they can explain again. Some cancer treatments are complex, so it's not unusual to need repeated explanations. It's a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion. You may also find it useful to write a list of questions before your appointment.

People sometimes feel that hospital staff are too busy to answer their questions, but it's important for you to know how the treatment is likely to affect you. The staff should be willing to make time for your questions.

You can always ask for more time if you feel that you can't make a decision when your treatment is first explained to you.

# ***Hormonal therapies***

Hormones help control how cells grow and what they do in the body. The hormones oestrogen and progesterone can both encourage breast cancer cells to grow, but particularly oestrogen.

Hormonal therapies lower the level of oestrogen in the body, or block it from attaching to the cancer cells. They only work for women who have oestrogen receptor (ER) positive cancers. They are often the first treatment for women with ER-positive breast cancer when the cancer is mainly in the bones. But if the cancer has spread to other organs as well, you usually have chemotherapy first and then hormonal therapy.

**There are different hormonal therapies.**

**The type you have depends on:**

- Whether you have been through menopause or not.
- Other hormonal therapies you have had before.

Hormonal therapies are usually easy to take. You take most of them as tablets and the side effects are usually quite mild.

Side effects may be more troublesome in the first few months, but they usually get better over time. If you continue to have problems, talk to your breast care nurse or doctor. There are usually ways that side effects can be treated or managed.

Some side effects are similar to menopausal symptoms and certain hormonal therapies cause a temporary or permanent menopause.

It takes a few weeks or months before your doctors can tell how well your treatment is working for you. If one treatment doesn't work, or stops working, your cancer doctor may prescribe another type.

## **Hormonal therapy after menopause**

Although the ovaries no longer produce oestrogen after the menopause, women still make some oestrogen in their fatty tissue.

**If you have been through menopause (you are post-menopausal), your doctor may prescribe one of the following:**

- An aromatase inhibitor, such as anastrozole, letrozole or exemestane.
- An anti-oestrogen drug, such as tamoxifen or fulvestrant (Faslodex®).

**“I’m on letrozole and have been for about five months. Initially I had tummy cramps, but they faded away after a few weeks. The hot flushes are a pain but I make sure I always have a little fan in my bag for whenever a big one overtakes me! I do feel that they lessen a little the longer you’re on them. You can take tablets for the joint pain – if it gets bad, ask your nurse about them.”**

Marie

## **Aromatase inhibitors (AIs)**

AIs are the main hormonal therapy used in post-menopausal women. They work by stopping oestrogen being made in the fatty tissue.

You take them daily as a tablet. Side effects include tiredness, joint and muscle pain, and hot flushes. They can also cause bone thinning (osteoporosis) so your doctor may prescribe drugs called bisphosphonates to protect your bones.

## Anti-oestrogens

### Tamoxifen

Tamoxifen stops oestrogen from attaching to breast cancer cells and encouraging them to grow.

**You take tamoxifen daily as a tablet. The side effects may include:**

- Hot flushes and sweats.
- Weight gain.
- Tiredness.

**“The plan is to stay on tamoxifen  
for as long as it is effective.”**

Karen

Tamoxifen can slightly increase your risk of a blood clot and the risk of developing cancer in the womb.

When you take tamoxifen for secondary cancer in the bone, it may make the pain worse for the first few days.

### Fulvestrant

Fulvestrant is only used in women who are post-menopausal. You have it as an injection into a muscle in your buttock once a month. Doctors may prescribe it after other hormonal therapies have already been tried. The side effects are similar to tamoxifen.

## ***Hormonal therapy before the menopause***

Before menopause, the ovaries produce oestrogen. If you haven't been through the menopause (pre-menopausal), your doctor may prescribe one of the following:

- The anti-oestrogen drug tamoxifen (see previous page).
- A drug, such as goserelin (Zoladex®), that stops the ovaries producing oestrogen (ovarian suppression).
- Surgery to remove the ovaries (ovarian ablation).

Pre-menopausal women usually have tamoxifen (see previous page) along with ovarian suppression or surgery to remove their ovaries. If tamoxifen stops working, your doctor may prescribe an aromatase inhibitor (see previous page) along with a drug that stops the ovaries working.

## ***Drugs that stop the ovaries producing oestrogen***

If you are pre-menopausal, you may be given a drug called goserelin (Zoladex®). It stops the pituitary gland in the brain from sending messages to the ovaries to produce oestrogen. This stops the ovaries producing oestrogen and causes a temporary menopause. Doctors sometimes call this ovarian suppression.

**The side effects are similar to menopausal symptoms and include:**

- Hot flushes and sweats.
- Joint pain.
- Low sex drive.

Your nurse will give you goserelin as a monthly injection under the skin of the tummy (abdomen).

## ***Removing the ovaries***

Removing the ovaries with a small operation will lower the level of oestrogen in the body. Doctors sometimes call this ovarian ablation.

You can usually have the operation with a short stay in hospital using keyhole surgery. The surgeon makes a few small cuts in the tummy area and inserts a long thin tube called a laparoscope that has a light and camera on the end. The surgeon removes the ovaries through the cuts using the laparoscope, which has small instruments attached to it. You usually recover quickly from this type of operation.

Your periods will stop straight away and you will usually have symptoms of menopause. This can be difficult when you're already coping with cancer. Knowing a treatment will make you infertile can be hard to cope with and to accept.

## ***Progestogens***

Drugs called progestogens may be tried after other hormonal therapies have already been given. These are similar to the female hormone progesterone. You usually have them as tablets. Megestrol acetate (Megace®) and medroxyprogesterone acetate (Farluta®, Provera®) are the ones commonly used.

The side effects include increased appetite, weight gain, feeling sick, slight vaginal bleeding (spotting) and rarely breathlessness. Let your doctor know if this happens.

# Chemotherapy

Chemotherapy is the use of anti-cancer drugs to destroy cancer cells. The drugs are carried in the blood and can reach cancer cells anywhere in the body.

**You usually have chemotherapy as your first treatment if:**

- The cancer does not have receptors for oestrogen (ER-negative).
- The cancer is in the liver or lungs.
- The cancer is growing quickly.

If you have had chemotherapy before, your doctors will choose a different drug or drugs. Women with HER2-positive breast cancer may have chemotherapy in combination with a targeted therapy drug. Your cancer doctor may invite you to take part in a clinical trial.

## *The drugs used*

Your cancer doctor or nurse will explain which drug or drugs are likely to be most helpful in your situation.

**The chemotherapy drugs commonly used to treat secondary breast cancer are:**

- Capecitabine (Xeloda®)
- Carboplatin
- Cyclophosphamide
- Docetaxel (Taxotere®)
- Doxorubicin (Adriamycin®)
- Epirubicin (Pharmorubicin®)
- Gemcitabine (Gemzar®)
- Paclitaxel (Taxol®)
- Vinorelbine (Navelbine®).

You usually have a single drug but some women may have two drugs given together.

Doctors may use some other chemotherapy drugs in certain situations. A drug called paclitaxel albumin (Abraxane®) is sometimes given after other chemotherapy drugs have been tried. You may also have it if you have had an allergic reaction to a taxane drug.

A drug called eribulin (Halaven®) may be given to women who have already had two other courses of chemotherapy.

Certain drugs may not be widely available in the public health system. You may have them as part of a clinical trial.

Your cancer doctor and nurse will explain which type of chemotherapy is appropriate for you. They will also talk to you about the benefits and the likely side effects of the drugs.



## ***How chemotherapy is given***

Chemotherapy drugs are given into a vein (intravenously), as injections or drips (infusions), or as tablets to take at home. You'll usually have your treatment in the chemotherapy day unit. Occasionally, the drugs are given through a soft, plastic line called a central line into a vein in your chest, through a thin tube inserted into your upper arm (a PICC line), or an implanted device in your chest called a porta-cath.

Chemotherapy is usually given as a session of treatment. After each session, you'll usually have a rest period of a few weeks before the next session. This allows your body to recover from the side effects. The chemotherapy session and the rest period make up a cycle of treatment. Your doctor or nurse will explain how many cycles of treatment are planned for you and how you'll be given your chemotherapy.

## ***Coping with side effects***

Advanced cancer and its treatments can produce a range of symptoms, so we provide some coping tips for the most common of these: nausea, pain, fatigue, breathlessness, poor appetite and depression/lowered mood. Your medical team will provide you with helpful information about symptoms you might expect, how to manage them and what to do if they become difficult or severe.

Some symptoms can become profound very quickly, so it is important to know which doctor, nurse or health professional you can contact, at any hour, if you need to.

## ***Controlling symptoms***

The symptoms of secondary breast cancer are usually relieved by treating the cancer. Sometimes this works quickly and you may notice an improvement within a few days. However, sometimes it may take a few weeks before you feel the benefit.

But there are also lots of other ways to relieve and control symptoms. Always let your doctor or specialist nurse know if you have new symptoms or if your symptoms get worse.

Many hospitals have doctors and nurses who are experts in treating pain and other symptoms.

## **Anaemia**

### **(reduced number of red blood cells)**

If chemotherapy reduces the number of red blood cells in your blood, you may become very tired and feel you have no energy. You may also become breathless and feel dizzy and light-headed. These symptoms happen because the red blood cells contain haemoglobin, which carries oxygen around the body.

If your haemoglobin is low, you may be offered a blood transfusion. You'll feel more energetic and any breathlessness will be eased.

## **Breathlessness**

Some people with advanced breast cancer may experience this side effect. It can be alarming when you are unable to catch your breath and feeling anxious can make it worse so contact your doctor or nurse right away and let them know.

Treatment will depend on the cause of the breathlessness. For example, there may be fluid around the lungs which can be drained or medicated. Radiotherapy scarring and the cancer can be causes too. Breathlessness responds well to treatment with small doses of morphine and oxygen.

### **If you experience breathlessness, try to relax and:**

- Get a draught across your face with a fan or air from an open window.
- Sit up or lean forward and rest on a table.
- Breathe with someone else - this can help to slow your breathing down.
- Sitting down when you're doing everyday things like washing, dressing or making food.

There are also controlled breathing or relaxation techniques that can help.

If cancer cells spread to the lining of the lungs (pleura), it can cause fluid to build up (called a pleural effusion), making you breathless. Your doctor can treat this by passing a narrow tube into your chest to drain off the fluid. This will improve your breathing straight away.

To stop fluid from building up, your doctor may use a treatment called pleurodesis. They use a sterile talcum powder to seal the two layers of the pleura together to prevent fluid from building up.

## ***Bruising and bleeding***

Chemotherapy can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot. If you develop any unexplained bruising or bleeding, such as nosebleeds, bleeding gums, blood spots or rashes on the skin, contact your doctor or the hospital straight away.

## ***Chemotherapy Side effects***

Chemotherapy drugs may cause unpleasant side effects, but these can be well controlled with medicines and will usually go away once treatment has finished. Not all drugs cause the same side effects and some people may have very few. You can talk to your doctor or nurse about what to expect from the treatment that's planned for you. The main side effects are described here as well as some ways to reduce or control them.

## ***Constipation***

This can be caused by some chemotherapy drugs, anti-sickness drugs and, often, by painkillers. Your doctor can prescribe a medicine to stimulate the bowel (laxative) for you.

### **Things you can do to help are:**

- Eat more fibre in your diet.
- Drink plenty of fluids.
- Be more physically active if you can – short, regular walks can improve constipation.

## ***Contraception***

Your doctor will advise you to use effective contraception. This is because the drugs may harm a developing baby. You can talk to your doctor or specialist nurse about this.

## ***Depression/lowered mood***

Dealing with the various symptoms and side effects of cancer and treatments can be all-consuming and depressing at times. Negative thoughts and feelings, a loss of mental acuity, lowered self-esteem, and a loss of motivation and confidence can occur from time to time and these are normal responses. Moderate exercise, or having something positive to focus on or look forward to can help but if you feel you cannot cope and these feelings intensify, then do seek help from your medical team. They can recommend someone for you to speak to. Most divisions of the Cancer Society have free counselling services for cancer patients.

## ***Diarrhoea***

Your doctor can prescribe drugs to control this. Make sure you drink at least two litres of fluids every day if you have diarrhoea. Follow the advice you were given and let your doctor know if the diarrhoea is severe or doesn't improve.

## ***Early menopause and menopausal symptoms***

Chemotherapy can affect the ovaries and bring on an early menopause. Hormonal treatments can also cause a temporary menopause or menopausal symptoms.

Hormone replacement therapy (HRT) isn't recommended because it contains oestrogen. This may encourage breast cancer cells to grow. But some doctors may prescribe HRT in situations where symptoms are severe and nothing else has helped. It's important to talk this through with your specialist doctor or nurse so that you're clear about the possible risks and benefits.

## ***Feeling sick***

Some chemotherapy drugs can make you feel sick (nauseated) or possibly be sick (vomit). Your cancer specialist will prescribe anti-sickness (anti-emetic) drugs to prevent this. Let your doctor or nurse know if your anti-sickness drugs are not helping, as there are several different types you can take.

Your doctor can prescribe different anti-sickness drugs. You usually take them by mouth. But they can also be given as a skin patch, suppositories, or injections under the skin.

### **Remember to:**

- Take your anti-sickness drugs as prescribed, usually regularly about 20–30 minutes before meals.
- Let your doctor or nurse know if the drug you are taking isn't working, so they can prescribe a different one.

### **Other things that may help include**

- Adjusting your diet.
- Relaxation techniques.
- Drinking dry ginger ale or ginger tea, and eating plain biscuits.

## ***Hot flushes and sweats***

Low doses of antidepressants, such as paroxetine and fluoxetine, can reduce hot flushes. These aren't prescribed if you're taking tamoxifen as they can interfere with how it works. An anti-depressant called venlafaxine can be given instead.

## ***Hair loss***

Some chemotherapy drugs may cause hair loss. Some people may have complete hair loss including eyelashes and eyebrows. Others may only experience partial hair loss or thinning. It depends on what chemotherapy drugs you are having (your doctor or nurse can tell you more about what to expect).

If you do experience hair loss, your hair should start to grow back within about 3–6 months of the end of treatment. It may grow back straighter, curlier, finer, or a slightly different colour than it was before. Your nurse can give you advice about coping with hair loss and how to look after your scalp.

## ***Infertility***

Becoming infertile can be very hard for some women to live with, whether they already have children or not.

Some women may find it helpful to talk through their feelings with a trained counsellor. If you need more specialised help, your doctor can arrange this for you.

## ***Lymphoedema (swelling of the arm)***

Some women may have lymphoedema as a result of treatments or because the cancer is blocking the lymph nodes in the armpit.

There are effective ways of reducing the swelling and managing lymphoedema. If you notice any swelling in your arm or hand, always let your specialist doctor or nurse as soon as possible.

The Lymphoedema Therapists Organisation's website is a good resource, see [www.lymphoedemanz.org.nz](http://www.lymphoedemanz.org.nz).

Some physiotherapists specialise in lymphoedema management. You can find information about them on our website **[www.sweetlouise.co.nz](http://www.sweetlouise.co.nz)**.

## ***Mouth problems***

Chemotherapy can cause mouth problems such as a sore mouth, mouth ulcers or infection. Drinking plenty of fluids, and cleaning your teeth regularly and gently with a soft toothbrush can help to reduce the risk of this happening. Your chemotherapy nurse will explain how to look after your mouth to reduce the risk of problems. They can give you mouthwashes, medicines and gels to help.

## ***Numb or tingling hands or feet***

These symptoms are caused by the effect of some drugs such as Paclitaxel, docetaxel, paclitaxel albumen and vinorelbine on the nerves. It's called peripheral neuropathy. You may also find it hard to fasten buttons or do other fiddly tasks.

Always tell your doctor if you have these symptoms. They sometimes need to lower the dose of the drug. The symptoms usually improve slowly after treatment finishes but in some people they may never go away. Talk to your doctor if you are worried about this.

## ***Other effects***

Menopausal symptoms can also include a lower sex drive, mood swings, lack of confidence, and a loss of concentration and memory.

## Pain

Pain depends on the location of the cancer and its size and can, in most cases, be effectively controlled. It may take some time to find the pain control that works best for you. The frequency and levels of pain can vary. Maybe it is worse at certain times, or you'll notice that one pain medication works better than another (it can be helpful to keep a 'pain diary').

Pain medicines are best used regularly 'to keep pain away', perhaps with additional pain medicine for 'breakthrough' pain. Some patients hold off using pain relief until it is really bad but this is not usually a good idea as extra medicines are then needed to get the pain under control. Poor pain control worsens quality of life for both the patient and carer(s). Energy that your body spends on dealing with pain could be more useful helping to deal with the cancer or in doing activities that you enjoy.

Many people are especially concerned about the group of drugs called opioids (such as morphine) and their addictive quality. This is only an issue if they are being used recreationally. If they are being used for pain, your body will use them properly and you will not get addicted. Your body can get used to them however, and you may need to increase the dose over time in order to get the same good effect. This is normal. People can be on very high doses of opioids and still function well.

### **Pain management is a specialised field and can include:**

- A wide range of analgesia medications from Panadol to stronger drugs such as morphine and codeine.
- Use of chemotherapy and/or radiotherapy to alleviate pain.

Your doctor will provide extensive information about the drugs and procedures he or she would like to use for your pain management.



## *Poor appetite*

This is a common side effect and can result from treatment, lack of physical activity, nausea and fatigue. You may find your eating habits change - foods that used to taste good no longer do and sometimes you may not want to eat at all.

### **Here are some tips that may help:**

- Try to eat small amounts regularly.
- Follow your impulse! If you crave something, give it a go!
- Cold food is easier to tolerate than hot and has less food smell.
- Keeping up fluid intake is important - try sipping clear liquids, broths and other drinks that take your fancy.
- Smaller amounts of food look encouraging on smaller plates and emptying a half-full glass feels better than being unable to empty a full one.
- Check with your nurse to see if you can take liquid drinks such as Ensure.
- Avoid foods that are fatty, sugary and spicy.
- If you have mouth ulcers, do let your doctor know - they can be treated. Moist foods such as scrambled egg can be less irritating to ulcers.
- Constipation can be worsened by pain medications so speak with your team about this. Feeling constipated can affect your appetite too.
- In some areas Sweet Louise offers Nutrition Support, these are providers where Sweet Louise vouchers can be redeemed. Please telephone **0800 11 22 77** for more information.
- An appointment with a dietician could help you choose food options that can work for you - your medical team should be able to provide some contact details. The Cancer Society also provides a very useful booklet (available free from your local Division of the NZ Cancer Society. Call **0800 CANCER** for more information).

## ***Risk of infection***

Chemotherapy can reduce the number of white blood cells, which help fight infection. If the number of your white blood cells is low, you'll be more prone to infections. A low white blood cell count is called neutropenia.

**Always contact the hospital immediately on the 24-hour contact number you've been given and speak to a nurse or doctor if:**

- You develop a high temperature – this may be over 37.5°C or over 38°C depending on the hospital's policy – follow the advice that you have been given by your chemotherapy team.
- You suddenly feel unwell, even with a normal temperature.
- You feel shivery and shaky.
- You have any symptoms of an infection such as a cold, sore throat, cough, passing urine frequently (urine infection) or diarrhoea.

If necessary, you'll be given antibiotics to treat any infection. You'll have a blood test before each cycle of chemotherapy to make sure your white blood cells have recovered. Occasionally, your treatment may need to be delayed if the number of your white blood cells is still low.

## ***Soreness and redness of palms of hands and soles of feet***

This is called palmar-plantar or hand-foot syndrome. It gets better when treatment ends. Your doctor or nurse can give you advice and prescribe creams to improve the symptoms. It can help to keep your hands and feet cool and to avoid tight-fitting socks, shoes and gloves.

**“ I did go through a very low period just after finishing chemo but I got through that and now it feels great to be alive. ”**

Wendy

## ***Sex***

If you have sex within the first couple of days of having chemotherapy, you need to use a condom. This is to protect your partner in case there is any chemotherapy in semen or vaginal fluid.

## ***Taking a break from treatment***

Keeping secondary breast cancer under control involves regular cycles of treatment over long periods of time. Sometimes the side effects of repeated treatments are very challenging and it can be difficult to maintain a lifestyle balance. Many people take a break from treatments so they can, for example, enjoy a special holiday or an extended rest without having to manage side effects. If considering a break, speak with your medical team about it because quality of life - and enjoyment of life - is important too.



## **Tiredness**

One of the most profound and constant side effects can be fatigue. Always feeling tired can be physically and socially limiting and can be very difficult for patient and caregivers alike. Fatigue can have a number of causes including:

- Chemotherapy and/or radiotherapy.
- The cancer itself.
- Inability to sleep.
- Anaemia.
- Stress and anxiety over your situation.
- Pain relieving drugs and sedatives.

Managing this type of fatigue can be difficult. Some patients liken it to feeling 'disconnected from the power source' and being 'completely drained' of energy. Causes such as anaemia and infection can be treated so be sure to discuss your situation with the medical team.

### **Here are some tips that may work for you:**

- Help others to understand how you feel by talking to them about it.
- Conserve the energy you do have for the activities you really enjoy - energy levels are usually highest in the morning.
- Taking high calorie/protein drinks can help maintain muscle tone and weight.
- Exercise as best you can, even if it is just a walk to the letterbox.
- Take little naps during the day.

## **Vaginal dryness**

Non-hormonal creams and water-based lubricants can help to reduce discomfort from vaginal dryness during sex.

There are also pessaries and creams that contain a small amount of oestrogen, which may be prescribed in low doses. Many breast specialists think only a very little oestrogen from the creams and pessaries is absorbed by the body. Talk this over with your doctor first.

## **Steroids**

You may have steroids as part of your treatment or to control symptoms and help you to feel better.

### **Steroids may be given:**

- With certain chemotherapy drugs to prevent an allergic reaction or to reduce sickness.
- To reduce swelling and control pain when there is a secondary cancer in the liver.
- To reduce pressure and relieve headaches and sickness when there is a secondary cancer in the brain.

They are usually only given for short periods of time so the side effects aren't usually too troublesome.

### **Possible side effects include:**

- Indigestion – take your steroids with food as prescribed.
- Having increased energy or feeling restless – let your doctor or nurse know if this is a problem.
- Difficulty sleeping – try taking your steroids earlier in the day.
- Increased appetite and weight gain – talk to your specialist nurse or a dietician if you're concerned about this.
- A higher level of sugar in the blood – you may have blood tests or your urine checked for this.

Sometimes steroids are given in high doses and are gradually reduced after you've had treatment with radiotherapy or chemotherapy.

### **Having higher doses of steroids for a longer period may cause more side effects. These can include:**

- Mood swings.
- Weight gain.
- Swollen feet or legs due to fluid retention.
- Being more likely to get an infection.

Talk to your doctor or specialist nurse if you are concerned about side effects you are having.

# ***Radiotherapy***

Radiotherapy uses high-energy rays to destroy cancer cells, while doing as little harm as possible to normal cells. It is used to relieve pain and other symptoms when breast cancer has spread to the bones or to the brain.

Radiotherapy is usually given as a series of short, daily treatments, Monday–Friday, in the radiotherapy department. The treatment will only take a few minutes. You may need only one or a few sessions of treatment. Radiotherapy isn't painful, but the position you have to lie in during the treatment may be uncomfortable. Taking a painkiller half an hour before your radiotherapy may help.

Radiotherapy doesn't make you radioactive and it's perfectly safe to be with other people, including children, after treatment. If you have any questions about radiotherapy, you can ask your doctor or the staff in the radiotherapy department.

## ***Side effects of radiotherapy***

When you have radiotherapy to improve symptoms, the side effects are not usually too troublesome.

Radiotherapy can make you feel tired. This sometimes lasts for a few weeks after treatment finishes. Other side effects depend on the area of your body being treated and how much radiotherapy you have.

Always tell your nurse or radiographer about any side effects. There are usually ways in which they can be treated or managed. Side effects stop or improve gradually when treatment finishes.

## ***Radiotherapy to the bones***

Radiotherapy can shrink a secondary cancer in the bones, strengthen the bone and reduce pain. It may take 3–4 weeks before it works so you need to carry on taking painkillers during this time.

Feeling very tired is a common side effect. This should gradually improve a few weeks after treatment finishes. Try to pace yourself and get as much rest as you need. It helps to balance this with some gentle exercise, such as short walks, if possible.

You may feel sick if the area treated is close to your tummy, for example the ribs or spine. Your doctor can prescribe anti-sickness drugs to control any sickness.

## ***Spinal cord compression***

Doctors also use a short course of radiotherapy to the spine when a tumour is close to or pressing on the spinal cord. This is called spinal cord compression.

It can cause different symptoms including pain around the chest and difficulty walking. Spinal cord compression is not common but needs to be treated quickly to prevent permanent damage to the nerves.



## ***Radiotherapy to the brain***

Radiotherapy helps to shrink a secondary cancer in the brain and improve the symptoms. You may have up to two weeks of treatment.

It causes some hair loss but this is usually temporary. Your hair should start to grow back within a few months after the treatment has finished. The skin on your scalp may also become dry and feel irritated. Your nurse or radiographer will give you advice on looking after the skin.

You may feel very sleepy or drowsy for a few weeks. Tiredness can continue for weeks or months after treatment. Get plenty of rest but try to take regular short walks to help give you more energy.

Radiotherapy to the brain may make you feel sick or be sick. Your doctor can prescribe anti-sickness tablets or steroids to control this.

Occasionally a type of radiotherapy called stereotactic radiotherapy is used to treat small brain tumours. But it is only available in some specialist hospitals and isn't suitable for everyone. It delivers high doses of radiation accurately targeted to the tumour causing less damage to surrounding tissue.

## ***Bone-strengthening drugs***

Bisphosphonates and denosumab are drugs that strengthen the bones. They also relieve bone pain and reduce the risk of a broken bone (fracture). You can also have them to treat high levels of calcium in the blood (hypercalcaemia).

If you have secondary breast cancer in the bones, your doctor may prescribe a bisphosphonate drug or denosumab to protect your bones. They help to reduce the risk of developing further problems.

You usually have bisphosphonates as a drip (infusion). The main bisphosphonate used is zoledronic acid (Zometa®) – given as a drip every 3–4 weeks.

Denosumab (Xgeva®, Prolia®) is a type of monoclonal antibody. You have denosumab as an injection under the skin every four weeks. The side effects can include diarrhoea, skin rash and flu-like symptoms.



## ***Bisphosphonate side effects***

The side effects are usually mild. They can include feeling sick, headaches, and flu-like symptoms such as chills and muscle aches

If you have bisphosphonates by drip, you may find the pain in your bones get worse for a short time. Your doctor can prescribe painkillers until this wears off.

Very rarely, bisphosphonates and denosumab can damage the bone (osteonecrosis) in the jaw. It's important to tell your cancer doctor straight away if you have any problems with your teeth or jaw.

Your doctor will ask you to have a dental check-up before starting treatment with bisphosphonates or denosumab. Dental treatment or dental problems can increase the risk of osteonecrosis of the jaw. Always tell your dentist you are taking bisphosphonates or denosumab.

## ***Too much calcium in the blood (hypercalcaemia)***

Secondary cancer in the bones can cause calcium to go out of the damaged bone and into the blood.

High levels of calcium in the blood can make you feel very tired and thirsty, and you may pass lots of urine. You may also feel sick or become irritable and confused. Tell your doctor or nurse if you have these symptoms. It's important hypercalcaemia is diagnosed quickly so that it can be treated.

Your nurse or doctor will give you a drip (infusion) of fluids to help to flush out the extra calcium from your body. They also give you bisphosphonates as a drip to lower the calcium levels. Your symptoms should go away within a couple of days.



## **Targeted therapies**

Targeted therapy drugs interfere with signals that tell the cancer cells to grow. Some drugs also stop the cancer from developing new blood vessels. There are different types that work in slightly different ways. Targeted therapies are sometimes called biological therapies.

You usually have targeted therapy drugs with chemotherapy. They are also occasionally given with hormonal therapy.

Trastuzumab (Herceptin®) and Pertuzumab are the only targeted therapy drugs available through the public health system to treat secondary breast cancer. Even if you have had treatment with trastuzumab previously, your cancer doctor may still recommend further treatment with it. This usually depends on how long ago you had it.

Trastuzumab and other targeted therapy drugs are sometimes given in clinical trials.

## **Trastuzumab (Herceptin)**

You may be treated with trastuzumab if you have HER2-positive breast cancer. It locks on to the HER2 protein and blocks the receptor. This stops the cancer cells from dividing and growing.

You can have trastuzumab every three weeks as a drip (infusion) or as a small injection under the skin.

**The side effects are often mild but some women may have:**

- Flu-like symptoms.
- Diarrhoea.
- Headaches.
- An allergic reaction.

Trastuzumab may cause damage to the heart. You have tests to check your heart before and during treatment. If it causes any heart problems, your doctor may prescribe drugs to treat these or stop trastuzumab for a while.

If trastuzumab is no longer controlling the cancer, your doctors will look at other treatments for you. But if you are having trastuzumab and the cancer spreads to the brain or spinal cord (central nervous system), you can usually continue taking it. Your doctor will give you other treatments to control the cancer in the central nervous system (CNS).

***“I remember asking my oncologist how long Herceptin worked. He explained that it was different for everyone but he had a patient who had been on Herceptin successfully for several years, which was encouraging”***

Karen

## **Other targeted therapy drugs**

The following drugs are not widely available in the public health system. You may be given them as part of a clinical trial.

### ***Pertuzumab***

Pertuzumab is a monoclonal antibody drug that is usually given with trastuzumab and the chemotherapy drug docetaxel. It is only used if you have HER2-positive breast cancer. You have it as a drip every three weeks. This is fully funded for HER2+ patients.

### ***CDK4/6 inhibitors – Palbociclib (Ibrance)***

Recently research has shown that CDK4/6 inhibitors (only palbociclib currently available in NZ) can reverse the endocrine resistance that otherwise inevitably occurs for some people. They are given together with another endocrine drug (letrozole or fulvestrant) and can control the disease for several months longer than the endocrine drug given alone.

### ***Trastuzumab emtansine (Kadcyla®)***

This drug is a combination of trastuzumab and a chemotherapy drug called emtansine. Trastuzumab delivers the chemotherapy to the cancer cells. You have it as a drip every three weeks. You need to have had previous treatment with trastuzumab and docetaxel or paclitaxel.

Lapatinib (Tyverb®) Lapatinib is used in women with HER2-positive breast cancer. You take it as a tablet. It can be given in combination with the chemotherapy drug capecitabine (Xeloda®), or with an aromatase inhibitor.

Bevacizumab (Avastin®) Bevacizumab is a monoclonal antibody drug that stops the cancer from developing new blood vessels. This may shrink the cancer or stop it from growing. It can be used to treat women when the cancer hasn't got receptors for HER2 or for hormones. This is called triple negative breast cancer.

You have bevacizumab as a drip (infusion) every 2–3 weeks. It's usually given with the chemotherapy drug paclitaxel.

### ***Everolimus (Afinitor®)***

Everolimus may be given to women with oestrogen receptor-positive breast cancer that is HER2-negative. You have it with the hormonal drug exemestane, but only if you have already had an aromatase inhibitor drug. You take everolimus as a tablet.

## ***Surgery***

Surgery is rarely used to remove secondary breast cancer. This is because the cancer isn't usually confined to one area. But it can occasionally be used in certain circumstances.

### ***Surgery to strengthen a weakened bone***

If a secondary breast cancer has weakened a bone, usually in the hip or leg, you may need an operation to strengthen it.

You have this under a general anaesthetic. The surgeon puts a metal pin into the centre of the bone and may fix a metal plate to it. The pin and plate stay in, permanently holding the bone in place and preventing it from breaking.

Surgery can also be used to replace a hip joint if it is affected. Occasionally it is used to treat secondary cancer in the spine.

You need to stay in hospital for a week or longer after the operation so you can recover fully. But most women can get up and start walking a couple of days after surgery. You usually have radiotherapy to the bone afterwards.

### ***Liver surgery***

Very occasionally, it may be possible to operate to remove a small cancer in a single area of the liver. This is major surgery that is carried out by a specialist liver surgeon.

Another treatment called radiofrequency ablation may be used instead of surgery, but this is not a standard treatment. It destroys cancer cells using heat by placing needle electrodes into the liver.

## ***Brain surgery***

Occasionally, it may be possible to have surgery to the brain. This is usually if there is only a single tumour in the brain in an area where it is possible to operate.

You will be referred to a specialist brain surgeon (neurosurgeon) to assess whether surgery is possible. The surgeon and specialist nurse will tell you what to expect before and after your operation. You'll usually be in hospital for at least a week.

Your doctor will prescribe steroids to reduce the swelling around the tumour and improve your symptoms. You take them before your operation and for a few weeks afterwards, depending on your symptoms. You usually have radiotherapy to the brain after you have recovered from the operation.



## ***What is palliative care?***

Palliative care offers patients comfort and support to help them live as well as possible with an incurable disease. There is a popular misconception that palliative care is only for end of life but its provision is appropriate at any stage of advanced cancer. Palliative care nurses and doctors not only work with physical discomforts (such as pain and nausea) but also provide support for the family too and coordinate services with your medical team, GP, social services and community groups to provide patients with comprehensive care.

Palliative care can be provided within the home, hospital or Hospice and referrals for such care can be made by your medical team or GP. For a list of Hospice services in New Zealand, please see our Community Services Directory in Section 5.

## ***Making decisions about treatment and care***

Take time, talk it over and review all of the information before making a decision about your care. With a primary breast cancer, 'throwing the book' at it and giving it everything you had in spite of the side effects and impact on quality of life was worth it because the hope was to optimise the chance of cure... but when the cancer advances and is incurable, that goal is no longer realistic and it may seem better to choose an option which aims for control and a balance which can give quality of life and cause less distress and physical exhaustion. It is a very personal and individual choice.

Some people research treatment options extensively to help them make informed decisions. Others feel more comfortable letting their oncology team make the recommendations.

### **You may choose to:**

- Take everything that is offered and weather the side effects.
- Select from a range of treatments.
- Discuss the potential benefits of paying for a medical treatment that is not funded in New Zealand.
- Pursue alternative therapies (discuss carefully with your medical team).
- Do nothing and live life as best you can, as long as you can, with assistance from palliative care specialists.



# Talking to specialists

You may have a number of different doctors caring for you and it can be confusing sometimes about who is looking after what! There are medical oncologists (who look after drug treatment - chemotherapy and hormone therapy) and radiation oncologists (who deal with radiation and sometimes hormone therapy as well) and it is important to know who to contact if you need help or advice urgently.

## It is important to:

- Know who is coordinating your overall care - this could be your GP, your oncologist, the palliative care team doctor, or another specialist.
- Know who to contact if something unexpected happens or there is a problem.
- Feel you have clear, confident and open communication with your specialist(s).
- Not feel concerned about taking too much of their time.

If you find after a few visits that you cannot speak openly with a member(s) of your medical team, let them know. Sometimes they appreciate this feedback and will do better. If not, you always have the right to seek a second opinion from another specialist. You can be referred to someone else through your GP or a specialist and can ask for your medical records to be sent to the doctor providing a second opinion. Be sure to request your scans and x-rays, if you do not have them already, so you can take these with you to the new doctor(s).



*All medical providers (and alternative therapy providers, public or private, even if unregistered) have a legal obligation to provide services of a certain standard, as per the patient Code of Rights. The Nationwide Health and Disability Advocacy Service (NHDAS) promotes patient rights and helps to resolve complaints. If you feel your rights have been violated, you can call the NHDAS toll free, for confidential and free advice, on **0800 555 050** or visit their website at **[www.hdc.org.nz](http://www.hdc.org.nz)**.*

## ***Research – clinical trials***

Cancer research trials are carried out to try to find new and better treatments for cancer. Trials that are carried out on patients are known as clinical trials. These may be carried out to:

- Test new treatments, such as new chemotherapy drugs or targeted therapies.
- Look at new combinations of existing treatments, or change the way they are given to make them more effective or reduce side effects.
- Compare the effectiveness of drugs used to control symptoms.
- Find out how cancer treatments work.
- Find out which treatments are the most cost-effective.

Trials are the only reliable way to find out if a different type of surgery, chemotherapy, hormone therapy, radiotherapy, or other treatment is better than what is already available.

### ***Participation in clinical trials***

New drugs are continually under development for the treatment of cancer. These new therapies are tested for effectiveness in controlled clinical trials. Some trials are worldwide and others are conducted within certain countries. Your doctor will discuss your participation in a clinical trial only if there is one recruiting for which you may be eligible, and if the new treatment being tested is as good as or better than standard treatments. Participants in 'randomised clinical trials' are selected at random to receive either the best existing treatment or the new treatment.

*The decision to take part is always yours and if you agree to join a trial, be sure you understand the reasons for the trial and the implications for you of your participation.*

## ***Blood and tumour samples***

Blood and tumour samples may be taken to help make the right diagnosis. You may be asked for your permission to use some of your samples for research into cancer. If you take part in a trial you may also give other samples, which may be frozen and stored for future use when new research techniques become available. Your name will be removed from the samples so you can't be identified.

The research may be carried out at the hospital where you are treated, or at another one. This type of research takes a long time, and results may not be available for many years. The samples will be used to increase knowledge about the causes of cancer and its treatment, which will hopefully improve the outlook for future patients.

*Tessa*



# Employment

You may have been working when you were diagnosed and could be wondering whether or not to continue. Your decision will be based upon your health, your financial situation and your priorities in life.

Many women who feel well enough do keep working because they enjoy the social connections and the value they receive from a familiar working environment. Some women keep working because they need the income. Talk to your employer and see what is possible to enable you to keep working, if you want or need to. He or she may be able to offer reduced hours, time off for appointments, and of course discuss sick and annual leave entitlements with you.

You may find it difficult to tell your work colleagues and choose to share the diagnosis only with close colleagues or only your employer. Sharing the news could create a more supportive working environment for you - but the decision is always yours to make.

You may decide to make some changes in your working life - to stop work altogether, change jobs, work parttime or perhaps undertake some volunteer activities instead of work.

If you are self-employed, perhaps you can employ a sub-contractor to assist you.



*Most employers are supportive, but if you think yours may not be sympathetic, or you feel in danger of losing your job, then you can speak with either a union or Human Resources representative in your workplace or contact the Ministry of Business, Innovation and Employment (NZ government department) on **0800 20 90 20** or visit their web page to read about the personal grievance process at [www.dol.govt.nz/er/solvingproblems/resolving/](http://www.dol.govt.nz/er/solvingproblems/resolving/)*

Many employers also belong to EAP (Employment Assistance Programme) which provides counselling for employees. The reason for counselling does not just have to be work related, so can be used for support around your changing health.

# Well-being choices

## Complementary medicines and therapies

Complementary medicines are best used in conjunction with conventional care rather than in place of. These medicines sit outside of conventional medical interventions (such as chemotherapy and radiotherapy) but can offer significant benefits to those living with advanced breast cancer, helping to improve quality of life. It is very important to discuss the use of complementary medicines with your GP and specialist as they can sometimes 'fight against' conventional medical treatments. This is particularly true of hormonally-based complementary medicines which can reverse the benefit from hormonal chemotherapy drugs. Chinese herbal remedies particularly, may contain hormones.

Sweet Louise offers a range of complementary therapies approved by our Medical Advisor. Some of the most popular are Reflexology, Reiki and Massage. A combination of conventional medical treatments and some complementary therapies can be coordinated to improve and enhance overall well-being and quality of life. Some patients find that meditation and prayer provide good coping strategies too. Discuss the inclusion of complementary therapies in your care plan with your team.

*Marjorie and Isabella*



## Nutrition

Good nutrition is important during treatment, although sometimes the side effects of the treatments or the effects of illness can make it difficult to eat and drink all that your body requires.

Treatment and illness side effects can include loss of appetite, nausea, dry mouth and indigestion. Also, some foods may not taste quite the same and you may also find certain foods and/or drinks you used to enjoy are just not appealing for a period of time.

There are some liquid nutritional supplements available which can provide the body with good nutrition during those periods when it is difficult to eat well and there may also be some dietary and herbal supplements you would like to try. *However, any supplements of this type should be cleared by your GP or specialist first as they may reduce the effectiveness of conventional medical cancer treatments.*

Eating a variety of foods to keep you well-nourished will help you to feel better, have more energy and cope with the treatments. If you are unsure about your diet, speak with your GP or specialist, or ask to be referred to a Dietitian for advice before making any major changes.

**“ I have come home (from golf) feeling energised from exercise, fresh air, good company, an ice cold beer inside and an appetite. Silver lining. ”**

Liz

The Cancer Society of New Zealand have an informative booklet called 'Eating Well During Cancer Treatment (2012)'. Ask your Sweet Louise Support Coordinator or local Cancer Society for a copy of the free resource.

## Exercise options

Regular exercise is an important part of being as healthy as you can be. Recent studies have shown that regular and appropriate exercise can improve quality of life for cancer patients. Most studies have focussed on women with a primary breast cancer diagnosis but popular feeling is that the benefits those women experience can also be enjoyed by women living with advanced cancer. Exercise is the best known way of combating fatigue, other than reducing the medications which may be making it worse, but exercise should not cause pain and should be stopped if it does.

**There are three basic types of exercise:**

**Aerobic** - increases heart and breathing rate, works muscles

**Flexibility** - stretching including Yoga, Pilates, Tai Chi

**Strength/Resistance** - using weights or stretch bands

The location of your cancer and its physical symptoms may determine the exercise you choose so speak to your medical team before you start. Always listen to your body and make sure that you're enjoying the activity. Exercise could be walking, biking, yoga and even dancing! It should be fun - exercise releases endorphins which make you - and your body - feel better. Regular and appropriate exercise can improve sleep, enhance relaxation and improve mood.

**It can be hard to stay motivated once you begin a routine because there are good and low days. Here are a few tips to keep you going:**

- Make it fun - exercise with others and have a coffee afterwards.
- Enjoy the solitude of a walk - it's a time for contemplation.
- Alternate the types of exercise you undertake (e.g. walking one day, yoga the next).
- Reward yourself for doing well with your exercise - perhaps a special massage treat!
- Talk to others and see what type of exercise has worked for them - compare notes.
- Listen to your body and take a break from exercise if you need to - be kind to yourself, especially during treatment.
- Remember - it's never too late to start, so give it a go!

*My Notes*





A photograph of a man and a woman embracing on a wooden pier. The man is wearing a light grey sweater and the woman is wearing a beige cable-knit sweater. They are both looking out over a body of water under a bright, hazy sky. The woman's hand, with a ring, is resting on the man's shoulder.

## **End of Life Matters**

*"There are no rules on how to behave as you approach the end of your life but there is no practice run either. This is it. People who are well sometimes say, 'If I was in your position I'd do this ...'; others say they don't know how they would react but hope they could be like me."*

Gabrielle



# *My Notes*

# ***Talking about and facing end of life***

It's a natural, human response to avoid speaking about death and dying because it can be upsetting to you and those close to you. But taking time to plan for what will happen when you die can bring a sense of relief, leaving you free to focus on living and enjoying the things that are important to you. Planning for death can be overwhelming, difficult, emotionally challenging, so do it when the time is right for you and your loved ones. Deciding on funeral plans, ensuring your will is current, and sorting out any important legal details can be most helpful for those caring for us.

Bringing up the subject of death can be difficult and sometimes those close to you may have a greater need to talk about it than you do. A way into the subject could be discussing beliefs about death and dying. This can lead the way to speaking about fears, uncertainties, making plans and ensuring your wishes are known.

## **The subject of death could be approached by discussing:**

- What happens when we die? Where do we go?
- Is there a God?
- Other experiences of death, perhaps of a family member, close friend.
- What will it be like to die?
- What are your fears - and the fears of those close to you?

End of life planning could mean making amends after a disagreement with someone, getting back in touch with people you haven't seen for a long time, telling a friend something you've always wanted to say - it is a time for healing and strengthening relationships and friendships that mean a lot to us.

It can also mean visiting a place that is special for you - your birthplace, the scene of a summer-sweet holiday you enjoyed one year - or making up a special album of old photographs and memories. Writing about your life can bring about a sense of accomplishment, completion and celebration and is something we can leave behind for others (writing about your life is a service many Hospices offer). Consider making a CD or DVD offered

by a Sweet Louise Service Provider; a service also offered by many Hospices as part of their family supportive care. It provides a lasting legacy, a treasure for loved ones we leave behind. Invite loved ones to a 'living wake' or a 'celebration of life' so you can participate and really enjoy the event and the time together.

The reality of death is difficult for those who love us too. They will need time to adjust and you may come to terms with your situation faster than they will.

Preparing for death is a personal journey so do what is right for you, at a time that is right for you.

***“A lot of people don’t want to face it. They seem to think I’m giving up but I’m not. No way am I giving up. I just want to be sure everything that is important to me is sorted. At least I’ve got a chance to do some things I want to do, put in place what I need to. I could get hit by a bus - some people die just like that and never have a chance to say goodbye but at least I have an opportunity to do that.”***

Jaime

## ***Making the decision to stop treatment***

Living with secondary breast cancer involves ongoing treatments, often over a number of years. In later stages, the cancer may spread further and treatments become less effective.

Sometimes you may ask yourself if the treatment is worth it. The physical effects of ongoing chemotherapy may give you one really good week a month. You may decide that you would rather have a greater measure of physical wellness instead, enabling you to spend quality time with family and friends without the appointments and ongoing side effects.

It's important to make an informed decision about cessation of treatment. Speak with your doctors, nurses, family and friends about the benefits of further treatment and the side effects. Take time to weigh it all up in your mind to where you feel able to make a choice that is right for you.

Those close to you may feel differently but remember the decision to stop is yours to make. If you feel conflicted, it may be helpful to speak with someone 'outside of the circle', a counsellor or psychologist, to help you work through the process.

***“ I’ve given up treatment now  
and feel the best I’ve felt in a long time. ”***

Annabel

# ***The role of Hospice***

A Hospice is a palliative care centre providing day and long term palliative care services for people with life threatening illnesses. A Hospice provides medical services but has a home-like feel and is staffed by medical professionals trained in palliative care.

People can go to Hospice to have pain or other symptoms brought under control before returning home, to give their caregiver some respite, or to spend their last days or weeks in a caring and comfortable medical environment.

Many Hospices also provide extra services (some are free or at minimal cost) such as art therapy workshops and yoga classes and have trained counsellors onsite who can assist with emotional and spiritual matters or advise on relationship difficulties.

The Hospice Team (doctors, nurses, social workers and counsellors) also make home visits to support patients and families.

Hospice Family Support social workers can provide information about community resources, advocacy and advisory services when dealing with Work and Income (WINZ), and offer guidance on future care options in your home or in residential care.

At end of life in Hospice, everything that can be done, will be done to keep you as free of pain and as comfortable as possible. Loved ones can visit at any time, day or night, and stay as long as they like. Some people express a wish to die at home and this is often possible with home visits from the Hospice palliative care team.



*To locate the Hospice in your area, and for further information about Hospice services, visit their website at **[www.hospice.org.nz](http://www.hospice.org.nz)**.*

## Practical aspects

*“ If things take a turn for the worst, my concern is that it will happen suddenly and I may not get a chance to put all that I want to in place. I’m planning to write a letter to my husband outlining the things I would like at my funeral because if you’re suddenly gone, they’re sad about you and then think, ‘Oh what did she want!’ It’s my last party so I want to be sure I have it the way I want! ”*

Jaime

## Advance care planning

Advance care planning helps you to think about and decide what treatment and care you might want at the end of your life. It is best to undertake this planning with those close to you, in consultation with your medical team if necessary, and at a time when you feel well. It can be reassuring to know that this has been taken care of, that our wishes have been recorded and that our family and medical team know what medical procedures we want if we are too ill to let them know or make decisions for ourselves.



The New Zealand website *Advance Care Planning* provides some helpful information and a planning template which is most helpful at [www.advancecareplanning.org.nz](http://www.advancecareplanning.org.nz)

## ***Making a will***

A will outlines who should receive possessions, property and assets after you die. A will outlines care decisions for your children and dependants, and can also include the arrangements for your funeral.

It is a good idea to make your will while you are well. Your solicitor can do this for you. By making a will, you can be sure that your last wishes are carried out and also that any special things you have can be given to the right people after your death.

If the distribution of your assets is straightforward, you can purchase a 'do-it-yourself' will kit (through the internet or from a books/stationery retailer) but if your assets are substantial and their division is complex, it is always advisable to have assistance from your solicitor.

Remember to let a family member or close friend know where you keep your legal documents and tell them how to contact your solicitor.



# Enduring Power of Attorney (EPA)

Nominating someone to hold enduring power of attorney for you is something to consider. This person should be someone you trust who can make decisions on your behalf if you are unable to do so. (Without an EPA, your family or friends will have to apply to the Family Court for permission to manage your affairs which can be expensive and stressful).

## Such decisions may include:

- Making decisions about your medical care and treatment (Personal Care EPA).
- Managing your financial arrangements (Property EPA).
- Managing your legal matters (Property EPA).



*Your solicitor can arrange EPAs for you or you can contact the Public Trust for assistance on **0800 371 471**, [www.publictrust.co.nz](http://www.publictrust.co.nz).*



## ***Your wishes***

You may have wishes you would like carried out and it is important to let those close to you know. Some of these wishes can be included in your Advance Care Planning.

### **You may:**

- Prefer to die at home, or in Hospice or hospital.
- Have specific ideas about your funeral.
- Wish not to be resuscitated.
- Prefer to have certain people caring for you, or with you when you die.
- Prefer to be free of pain and unconscious or tolerate some pain in order to stay conscious.

Put your wishes in writing, in consultation with your doctor and/or solicitor and those close to you, so everyone knows what you would like to happen when the time comes.

## ***Planning your funeral***

You can plan your own funeral if you prefer, so it will be conducted as you would like it to be. Your plan also ensures that family know exactly what you would like and do not have to guess. You can meet with a funeral home representative of your choice to discuss a plan with them or you can write down your plan and let those close to you know where it is. By planning your funeral you can be sure your favourite music is played, certain hymns can be sung, favourite readings or poems can be included, right down to the floral arrangements and the type of car to carry your casket. Most funeral directors will have a free pack of information they will send to you.

***“I arrived at 4pm with my list of ideas. I was greeted by a really friendly guy. We sat down in a very comfortable room and I explained that I had advanced cancer and wanted to arrange my funeral while I was still fully functioning. He didn't look fazed by anything I said and was able to answer all of my questions. I was pleasantly surprised with how well the whole meeting went in terms of ease and level of comfort. I felt listened to and understood. By 5pm I had expressed, discussed and clarified what I wanted to happen at my own funeral. By the time I arrived home I felt exhausted, emotional but most of all I had an enormous sense of achievement.”***

Angela

## ***You can leave a lasting gift to help others***

Many people choose to leave a gift in their will to a charity that has been a meaningful part of their lives. For Sweet Louise, bequests will enable us to continue supporting hundreds of members and their families affected by breast cancer.

Receiving a gift, no matter the size, makes a huge difference for us. It's very humbling when a member leaves us such a gift, as they are essentially supporting other members. If you were considering leaving a charitable gift in your will, we would very much appreciate you including Sweet Louise.

If you would like to discuss how to leave a gift to Sweet Louise, you can talk to your Support Coordinator or find more information on our website. Your privacy around such decisions will be respected by us all.



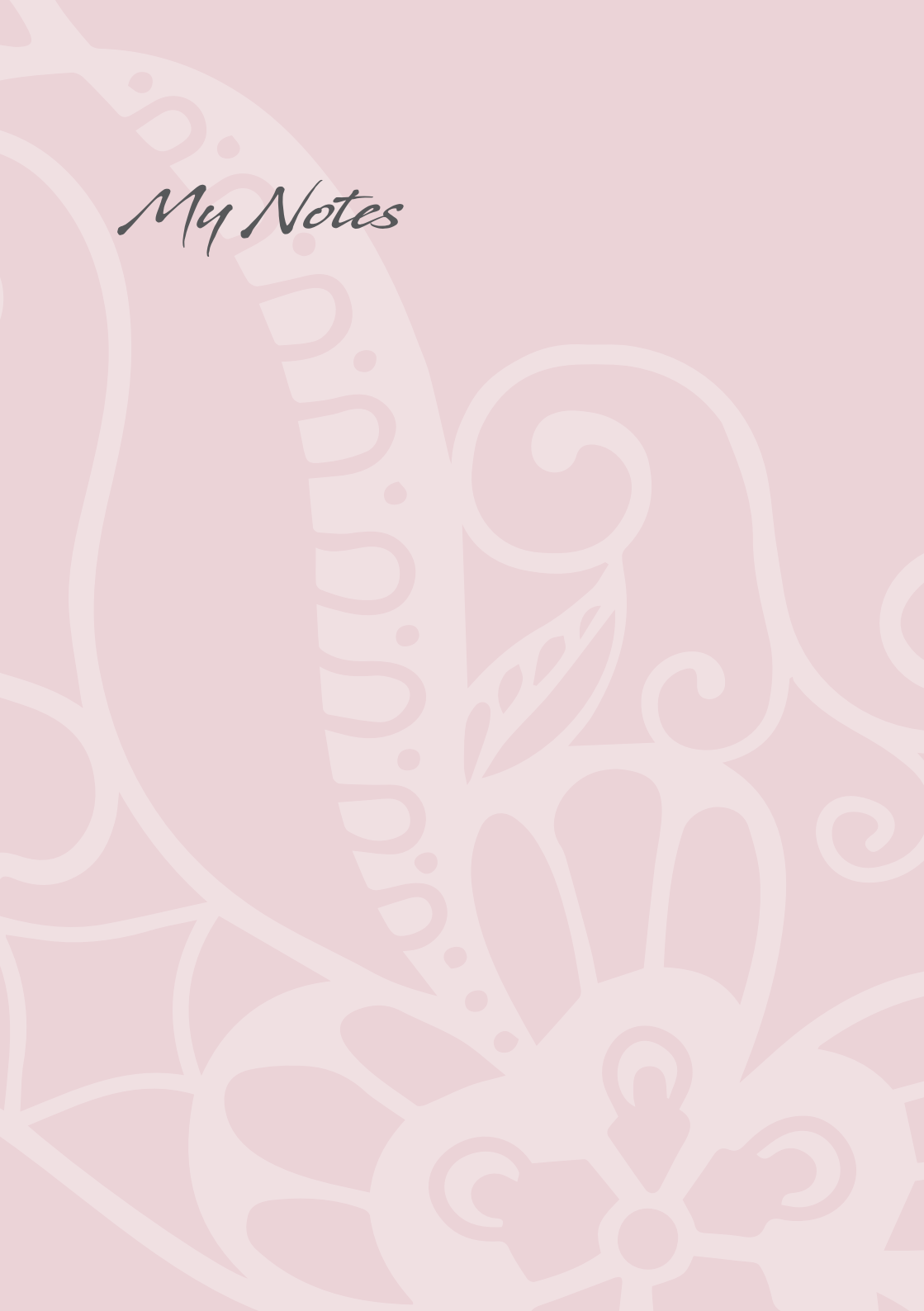
# ***Resources***

*A guide to community services and information*

*"Living everyday with love and laughter  
makes my world a better place"*

*Jayne*

*My Notes*



# Community services

## Advocacy, Needs Assessment, Mobility Parking

### **Nationwide Health and Disability Advocacy Service**

If you want to know more about your rights when using health and disability services, get questions answered or make a complaint, we can help you to find an independent advocate.

The Nationwide Health and Disability Advocacy Service is a free, consumer-focused service provided for under the Health and Disability Commissioner Act 1994. For help please phone **0800 555 050** or go to **[www.advocacy.hdc.org.nz](http://www.advocacy.hdc.org.nz)**.

### **Needs Assessment Services (NASC)**

This service is offered by District Health Boards across the country and can provide assistance if you have a disability following hospitalisation, if you have acute illness, or require palliative care. You can be referred by your oncology nurse, a Sweet Louise Support Coordinator, or your medical team.

### **Mobility Parking**

The Mobility Parking Permit Scheme offers parking close to facilities and shops for people who are unable to walk 200m unassisted. It can be for disabled people but also for people who are ill, temporarily using a wheelchair or other walking aid. To be eligible, you must either:

- Be unable to walk and be reliant on a wheelchair for mobility.
- Or rely on mobility devices (e.g. crutches, walking sticks, walking frames).
- Or be unable to walk more than 200 metres unassisted because of the nature/severity of your condition.

For an application form, contact your general practitioner, medical specialist, your nearest CCS branch or **[www.ccsdisabilityaction.org.nz](http://www.ccsdisabilityaction.org.nz)**. Mobility cards can only be issued with your doctor's signed approval.  
**0800 227 2255.**

**Sweet Louise Members can use their vouchers for transportation services. Please see listings in the Service Directory or contact your Support Coordinator.**

# ***Telephone services***

## ***CAB Language Link (Auckland area)***

Offers free confidential information, support, advice, and advocacy for people in 26 languages, either by phone, face to face or email. Phone **09 624 2550** (Auckland) or **0800 788 877** (nationwide), or email **language@cab.org.nz**.

## ***Healthline (Nationwide)***

Free advice available from trained registered nurses 24-hrs a day, seven days a week by phoning **0800 611 116**.

## ***St John's Caring Caller (Nationwide)***

This is a free telephone friendship service that put people in touch regularly with someone who cares about them. It is not a helpline. For information telephone **0800 785 646**.



# ***Web based directories***

## ***Central Cancer Network (CCN)***

**[www.centralcancernetwork.org.nz](http://www.centralcancernetwork.org.nz) 06 3508918**

The Central Cancer Services Directory helps health professionals and patients, carers, families and whanau affected by cancer to locate and access services. This directory covers services in the following district health board areas: Capital and Coast, Hawkes Bay, Hutt Valley, MidCentral, Tarawhiti, Taranaki, Wairarapa and Whanganui.

## ***Healthpoint Cancer Support***

**[www.healthpoint.co.nz](http://www.healthpoint.co.nz)**

Provides information on the cancer support services available in communities. Covers: Bay of Plenty, Canterbury, Central Auckland, Central Lakes, Dunedin – South Otago, East Auckland, Hawkes Bay, Hutt, Lakes, MidCentral, Nelson Marlborough, North Auckland, Northland, South Auckland, South Canterbury, Southland, Tairāwhiti, Taranaki, Waikato, Wairarapa, Waitaki, Wellington, West Auckland, West Coast and Whanganui.

## ***Midland Cancer Network***

**[www.midlandcancernetwork.org.nz](http://www.midlandcancernetwork.org.nz)**

The Midland Cancer Services Directory helps health professionals and patients, carers, families and whanau affected by cancer to locate and access services. This directory covers services in the following district health board areas: Waikato, Lakes, Bay of Plenty and Tairāwhiti District Health Board areas.

## ***Southern Cancer Network***

**[www.westcoastdhb.org.nz/links/southern\\_cancer\\_network](http://www.westcoastdhb.org.nz/links/southern_cancer_network)**

The Northern Cancer Services Directory helps health professionals and patients, carers, families and whanau affected by cancer to locate and access services. This directory covers services in the following district health board areas: Nelson/Marlborough, Canterbury, West Coast, South Canterbury and Southern District Health Board areas.

# ***Financial assistance***

## ***Benefits***

The hospital or hospice Social Worker is the best person to speak to regarding benefits and travel allowances to which you may be entitled. Ask your breast care/oncology nurse to help arrange an appointment.

## ***Breast Prosthesis Subsidy***

There is a government subsidy available for purchasing a suitable prosthesis and undergarments. Visit the website **[www.health.govt.nz](http://www.health.govt.nz)** or ask your oncology or breast care nurse to assist. There are a number of specialist shops nationwide that provide advice and assistance with selecting a prosthesis. Telephone Sweet Louise on **0800 11 22 77** for information.

## ***Wig and Hairpiece Subsidy***

There is a government subsidy available for those who have hair loss due to a medical condition or from some cancer treatments. The payments reduce the cost of purchasing and maintaining a wig, hairpiece or other related products. Contact **[www.health.govt.nz](http://www.health.govt.nz)** for information.

**Sweet Louise Members can use their vouchers for wigs/headwear and breast prostheses/undergarments. Please see listings in the Service Directory or contact your Support Coordinator.**

## ***Food***

It is possible to have frozen or fresh meals delivered to you in most areas. Your local division of the Cancer Society, or your local Hospice, may provide this service (at low cost or no cost).

**Sweet Louise Members can use their vouchers for Service Providers offering meal services. Please see listings in the service directory or contact your Support Coordinator for localities currently served.**

# **General information and palliative care services**

## ***The Cancer Society of New Zealand (Nationwide)***

The Cancer Society provides a wide range of professional services and programmes for cancer patients and their families. In some areas this may include accommodation and transport options (Volunteer Drivers) for patients and their family and, in some areas, frozen meals are available for cancer patients. To locate the office nearest you, phone the Toll Free Help Line **0800 CANCER (226 237)**.

### **The Cancer Society also offers:**

- CancerChat NZ an online chat forum, for people who want to 'talk' about their experiences with cancer. **[www.cancerchatnz.org.nz](http://www.cancerchatnz.org.nz)**.
- Cancer information library with books and other resources available for loan.
- Cancer Connect a peer support group.
- Counselling services for people with cancer, and their carers can be made by phoning **0800 226 237**. A doctor's referral is not required.

## ***Hospice NZ***

There are hospices providing palliative care services in the North Island: Northland, Auckland, Waikato, Bay of Plenty, Central North Island (Rotorua and Taupo), Taranaki/Wanganui, Hawkes Bay, East Coast, and Wellington/Lower Hutt and Manawatu. In the South Island: Nelson and Marlborough, West Coast, Canterbury, South Canterbury, Otago and Southland. Full information about individual hospices can be found on **[www.hospice.org.nz](http://www.hospice.org.nz)** or by phoning **04 381 0266**.

## ***Māori, Pacific and other ethnicities***

***Refer to [healthpoint.co.nz](http://healthpoint.co.nz) for regional support services***

- ***Cultural supports***
- ***Interpreting Services***
- ***eCald***

Migrant and refugee services. Providing support to immigrants and refugees primarily from Asia, the Middle East and Africa.

## ***Medical alarms***

There are several companies offering home medical alarms:

- The St John Medical Alarm service is designed to help New Zealanders live independently for longer. It's ideal for people with a health condition that might require emergency assistance.  
Telephone **0800 50 23 23** or **[www.stjohn.org.nz](http://www.stjohn.org.nz)**.
- BUPA also have a 24 hour response service.  
Telephone **0800 608099** or **[www.bupa.co.nz](http://www.bupa.co.nz)**.

# ***Cancer Society of New Zealand***

Your local division of the Cancer Society will have information about support available for women of other cultural and ethnic backgrounds - please call **0800 CANCER** for more information.

*Pauline*



# Support

## **Breast Cancer Aotearoa Coalition (BCAC)** **(Auckland and nationwide)**

The Coalition consists of a number of breast cancer-related Member groups (of which Sweet Louise is one) throughout New Zealand, led by a central committee, collectively advocating to make world-class detection, treatment and care available to all New Zealanders experiencing breast cancer. Visit **[www.breastcancer.org.nz](http://www.breastcancer.org.nz)** for more information and to receive a free copy of Step by Step, a helpful resource for those newly diagnosed with breast cancer.

## **Breast Cancer Support (BCS)** **(Auckland and nationwide)**

BCS offers support groups and one-to-one visits within the greater Auckland area and telephone support nationwide. All services are delivered by trained volunteers who have experienced breast cancer. If you live outside of Auckland, BCS can help to locate support services within your local area. To join a group, to find support in your local area, or to speak to someone who has experienced breast cancer, please phone us on **0800 273 222** or visit **[www.breastcancersupport.co.nz](http://www.breastcancersupport.co.nz)**.

Support groups are established in Warkworth, Hibiscus Coast, North Shore, Central Auckland, West Auckland, East Auckland, South Auckland, Waiheke Island, Franklin, Christchurch, Levin, Motueka, Rolleston, Balclutha and a young women's group in Auckland.

## **Breast Cancer Support Northland Trust**

This group offers practical and emotional support for those living in Northland. Contact **[info@breastcancernorthland.co.nz](mailto:info@breastcancernorthland.co.nz)** or **0800 227 687**.

### **Breast Cancer Support Service Tauranga (BCSSTGA) (Bay of Plenty)**

Breast Cancer Support Services Tauranga has a range of support services for women in the Bay of Plenty. Please contact **07 571 3346** or visit **[www.breastcancerbop.org.nz](http://www.breastcancerbop.org.nz)**.

### **Grief Centre**

This is an organisation with resources, counselling and groups available to help those dealing with grief and loss. It could be useful for you as well as for finding out what could help your family later. **[www.griefcentre.org.nz](http://www.griefcentre.org.nz)**.

### **Lymphoedema Support (Nationwide)**

The Website of New Zealand Lymphoedema Therapists **[www.lymphoedemanz.org.nz](http://www.lymphoedemanz.org.nz)** provides contact information for National Private Lymphoedema Therapists and District Health Board Lymphoedema Services throughout New Zealand. There are support groups in some areas - please call your local division of the Cancer Society (**0800 CANCER**) to see if there is one in your area. There is also a lymphoedema support network **09 625 6463** or **[lymphoedema.info@nzord.org.nz](mailto:lymphoedema.info@nzord.org.nz)**.

### **New Zealand Breast Cancer Foundation (NZBCF)**

The Foundation has a Specialist Breast Care Nurse, who is available weekdays by phoning **0800 226 877**.

NZBCF also funds three free counselling sessions for those undergoing treatment or living with secondary breast cancer. Please telephone **0800 226 8773** for more information.

### **Rotorua Breast Cancer Trust**

The Rotorua Breast Cancer Trust offers support and care for those affected by breast cancer in the Rotorua community. **022 424 6616**  
**[info@rbct.co.nz](mailto:info@rbct.co.nz)** or **[www.rotoruibreastcancertrust.co.nz](http://www.rotoruibreastcancertrust.co.nz)**.

## ***Other***

### ***Central Primary Health Organisation (PHO) Community Cancer Nurse's Service***

The Cancer Support Nurses provide a free service in the community delivering education, support, and co-ordination of care to both individuals and families with cancer.

Areas covered:

**Manawatu** phone **06 354 9107**

**Otaki** phone **06 364 8291**

**Horowhenua** phone **06 367 6433**

**Tararua** phone **06 376 8860**

### ***Cancer Psychology Service (Palmerston North)***

Psychologists work with people affected by cancer to improve the quality of their lives, by reducing stress, discussing coping strategies, improving adjustment and assisting with decisions about information needs, and treatment choices. Telephone **06 350 5180**, or visit **[www.cancer-psychology.massey.ac.nz](http://www.cancer-psychology.massey.ac.nz)**.



# Wellbeing

## Care Community Trust

The Care Community Trust offers free weekends at motel style units at Camp Raglan in the Waikato region. Stays are offered to people living with cancer in the Waikato and Bay of Plenty region, however if you live elsewhere some exceptions can be made on a case by case basis. Please contact your Support Coordinator to be referred.

**[www.carecommunity.org.nz](http://www.carecommunity.org.nz)**

## Casting for Recovery (CFR)

This organisation provides retreats during the late summer on both the North and South Island, at no cost to participants, which allow people whose lives have been profoundly affected by breast cancer to gather in a beautiful, natural setting and learn to fly fish.

**[www.castingforrecovery.org.nz](http://www.castingforrecovery.org.nz) or 027 2796766.**

## Hospice

Find out what programmes are offered by your local hospice. Many run a variety of wellness groups including art therapy, mindfulness, yoga, managing symptoms and side effects and some even offer walking groups. Some hospices also provide treatments such as massage and reiki etc. See **[www.hospice.org.nz](http://www.hospice.org.nz)** or call **04 381 0266** to find out where your local hospice is and what they offer.

## Look Good Feel Better

Look Good Feel Better is a free programme dedicated to teaching women with cancer, through hands-on experience, techniques to help restore and enhance their appearance during and after treatment. Look Good Feel Better is a step by step make-over session led by cosmetician volunteers. Call **0800 865 432** **[www.lgfb.co.nz](http://www.lgfb.co.nz)** for your nearest programme.

## ***Pinc & Steel***

Pinc & Steel are physiotherapists specially trained in cancer rehabilitation, They provide individual and group programmes designed to improve the strength, quality of life and sense of wellbeing for women and men diagnosed with cancer. Pinc & Steel physiotherapists are based throughout New Zealand, see their website for locations and details.

**[www.pincandsteel.com](http://www.pincandsteel.com)**

## ***Race4Life***

The aim of Race4LifeTrust is to enable people, living with life limiting illness, to realize dreams that they, and their families can cherish. Their mission is to make wishes come true. Race4Life services the whole of New Zealand.

**[www.race4life.co.nz](http://www.race4life.co.nz)**

## ***Ronald McDonald Family Retreat***

The Ronald McDonald Family Retreat in Rotorua provides one weeks free holiday accommodation for families who have experienced the impact of a chronic/long term illness or a bereavement in their family. The houses are beautiful and restful on the shore of Lake Rotorua and sleep up to eight people. **[www.rmhc.org.nz/retreat/](http://www.rmhc.org.nz/retreat/)**

## ***Time Out***

Time Out is a registered charity dedicated to providing free holiday accommodation for people with incurable illnesses and their whanau. Accommodation is available in many locations in New Zealand. To find out more information and to organise time away for you and your whanau, register on **[www.timeoutnz.org](http://www.timeoutnz.org)**

**Please speak with your Support Coordinator for other Wellbeing options and retreats in your area 0800 11 22 77.**

# ***Young women***

## ***Breast Cancer Support Service Tauranga Young Women's Group***

Breast Cancer Support Services Tauranga has a support group for young women. **Please contact 07 571 3346** or visit **[www.breastcancerbop.org.nz](http://www.breastcancerbop.org.nz)**.

## ***Breast Cancer Support Young Women's Group (Auckland)***

Breast Cancer Support has a support group for young women aged 25-45, meeting monthly in Auckland. If you live elsewhere in NZ, we can help you source local support. Please call us on **0800 273 222** for more information.

## ***Breast Cancer Nirvana***

Set up by a young woman with breast cancer, this site is interested in the support needed for women with breast cancer and has ideas and resources on what is useful and what is not. **[www.breastcancernirvana.co.nz](http://www.breastcancernirvana.co.nz)**.

## ***NZ Young Women's Online Forum***

The NZ Young Women's Forum is co-hosted by the Breast Cancer Network Australia, Breast Cancer Support and the Breast Cancer Network NZ at **[www.bcna.org.au](http://www.bcna.org.au)**. Create your own profile using 3124 as your post code. Using 'Find Groups', enter the key words 'New Zealand' and scroll down to locate the NZ Young Women's Group. If you have any problems registering please contact **[support@breastcancersupport.co.nz](mailto:support@breastcancersupport.co.nz)**.

## ***Shocking Pink***

Shocking pink is a Christchurch based group supporting young women with breast cancer. [www.shockingpink.org.nz](http://www.shockingpink.org.nz) or [info@shockingpink.org.nz](mailto:info@shockingpink.org.nz).

## ***Younger Women Breast Cancer Group***

For women in the Waikato area. Please call the Cancer Society's Hamilton office on **07 838 2027** or email [admin@cancersociety.org.nz](mailto:admin@cancersociety.org.nz).

## ***Whole Lotta Life Foundation***

The Whole Lotta Life Foundation is for people age 20-45 living with cancer (or diagnosed previously) and offers online support, regional meet-ups and retreats. [www.wholelottalife.org](http://www.wholelottalife.org).

# ***Children***

## ***Cloud Workshops***

This is an art based programme run in conjunction with Mercy Hospice in Auckland for bereaved children and those with life threatening illness in their family. It is for children aged 5-18. [www.cloudworkshop.co.nz](http://www.cloudworkshop.co.nz).

## ***Kenzie's Gift***

A charity committed to ensuring the ongoing psychological wellbeing of children who are impacted by serious illness in their families. They provide free one-to-one psychotherapy for children, plus a toolkit for parents. [www.kenziesgift.com](http://www.kenziesgift.com).

## ***Skylight***

For resources on helping children coping with a sick parent, see [www.skylight.co.nz](http://www.skylight.co.nz) This website has a number of books and pamphlets to help children and the adults supporting them. **0800 29 91 00**.

# Books and websites

## Books

There are many books written about breast cancer, nutrition as well as complementary therapies. We have a wide selection in our Sweet Louise library. To request a book from our library, please email **members@sweetlouise.co.nz** or telephone **0800 11 22 77** or use the form on our website at **www.sweetlouise.co.nz/library/**.

Your local division of the Cancer Society will also have a good resource library too - contact them for information about borrowing books and resources.

## Websites

A Google search will turn up a number of options so do be selective when accessing sites for information. Your oncologist or breast care nurse may give some suggestions. Here are a few that we use for up-to-date information and you may find them helpful too.

### New Zealand

- Breast Cancer Aotearoa Coalition (BCAC)  
- **www.breastcancer.org.nz**
- Breast Cancer Support Incorporated (BCS)  
- **www.breastcancersupport.co.nz**
- Cancer Society New Zealand - **www.cancernz.org.nz**
- Clinical Trials - **www.clinicaltrials.health.nz**
- Lymphoedema NZ - **www.lymphoedemanz.org.nz**
- The New Zealand Breast Cancer Foundation - **www.nzbcf.org.nz**

## ***Australia***

- Australian Breast Cancer Centre - [www.canceraustralia.gov.au](http://www.canceraustralia.gov.au)
- Breast Cancer Network Australia - [www.bcna.org.au](http://www.bcna.org.au)  
The site also has a very helpful page of downloadable pdfs on various topics of interest at:  
[www.bcna.org.au/fact-sheets-and-booklets#downloads](http://www.bcna.org.au/fact-sheets-and-booklets#downloads)
- McGrath Foundation - [www.mcgrathfoundation.com.au](http://www.mcgrathfoundation.com.au)

## ***England***

- Breast Haven - [www.thehaven.org.uk](http://www.thehaven.org.uk)
- Breast Cancer Care UK - [www.breastcancercare.org.uk](http://www.breastcancercare.org.uk)
- Cancer Backup - [www.cancerbackup.org.uk](http://www.cancerbackup.org.uk)
- Cancer Research UK - [www.cancerresearchuk.org.uk](http://www.cancerresearchuk.org.uk)
- Macmillan Cancer Support (UK) - [www.macmillan.org.uk](http://www.macmillan.org.uk)

## ***United States of America***

- National Cancer Institute USA - [www.cancer.gov](http://www.cancer.gov)
- Dr Susan Love - [www.susanlovemd.com](http://www.susanlovemd.com)
- Men with Breast Cancer - [www.johnwnickfoundation.org](http://www.johnwnickfoundation.org)

# ***Glossary of common terms***

Here is a list of some common terms you may hear with reference to your cancer and treatment. Contact the Sweet Louise Support Coordinators on **0800 11 22 77** or via email at **members@sweetlouise.co.nz** if you need help with other terms that are not listed here.

**Adjuvant treatment** - This is supportive/additional treatment for breast cancer e.g. chemotherapy, radiotherapy, hormone treatment, or Herceptin.

**Alternative therapies** - Treatments used instead of conventional medical treatments.

**Anaemia** - A condition where there are fewer red blood cells in the blood than normal.

**Analgesia** - Analgesics are commonly called painkillers.

**Anti-emetic** - Drug used to control nausea and/or vomiting.

**Aromatase inhibitors** - Aromatase inhibitors (AIs) can help block the growth of tumors by lowering the amount of oestrogen in the body.

**Ascites** - Accumulation of fluid in the abdominal or peritoneal cavity.

**Biopsy** - Removal of body cells or tissue for microscopic examination.

**Bone Scan** - An investigation that produces a picture of the bones.

**Chemotherapy** - Cancer treatment using intravenous and/or oral drugs. These drugs are sometimes called cytotoxic drugs.

**Complementary therapies** - Treatments or therapies that are used alongside conventional medical treatments to improve quality of life and well-being.

**Compression bandaging** - Compression bandaging, also called wrapping, is the application of several layers of padding and short-stretch bandages to the areas affected by severe lymphoedema.

**CT scan** - Computerised tomography x-ray providing a 3-D picture of the inside of the body.

**Echocardiogram** - An ultrasound test that examines heart shape, size and function.

**Haemoglobin** - This is the iron-containing pigment of the red blood cells. Its function is to carry the oxygen from your lungs to your tissues.

**Hand-foot syndrome** - A reaction to certain chemotherapy drugs typified by redness/tenderness/peeling of skin on palms of hands and soles of feet.

**HER2** - Also known as HER2-neu or c-erbB2 - a cell protein that allows a growth factor to bind to it, causing the cell to grow and divide.

**Hormonal therapies** - A family of drugs used to treat women with hormone receptor positive breast cancer.

**Hypercalcaemia** - A high level of calcium circulating in the blood.

**Intravenous infusion** - A procedure for infusing fluids, including drugs, into the bloodstream via needle or cannula, portacath, PICC, or Hickman line.

**Lymphatic vessels** - Vessels within the body that collect fluid and waste from tissues.

**Lymph nodes** - Located under the armpit and other parts of the body, help to collect waste and prevent infection.

**Lymphoedema** - Swelling of a limb or breast that can develop after treatment for breast cancer.

**Magnetic Image Resonance (MRI)** - Use of magnetic fields to produce an image of the inside of the body.

**Metastasis** - Name given to a cancer that has spread to other parts of the body.

**Multidisciplinary care** - A team approach by health care practitioners to your cancer care.

**PET scan** - Positron emission tomography - a scan to determine areas in the body where cells are more active than usual.

**Palliative care** - Treatments given to optimise quality of life treating an individual's physical, psychosocial, spiritual and cultural needs when facing a life-limiting illness.



**Pleural aspiration** - This involves the drainage of fluid around the lungs.

**Pleural cavity** - Space between the membrane that lines the rib cage and covers the lungs.

**Portacath** - A portacath is a small medical device that is surgically implanted beneath the skin. It is designed to facilitate access to the venous system, for patients who require frequent chemotherapy administration.

**Prognosis** - An assessment of the course and likely outcome of a person's disease.

**Radiotherapy** - Treatment for cancer in a particular area of the body, using high energy x-rays.

**Steroids** - Drugs used to relieve swelling and inflammation, and reduce nausea.

**Systemic treatment** - Treating the whole body to eliminate cancer cells (e.g. chemotherapy).

**Targeted therapies** - Drugs that prevent the growth of specific types of cancer cells.

**Transfusion** - Transfer of blood or blood products from a donor to another person.

**Ultrasound** - Use of sound waves to produce a picture of the inside of the body.

**White blood cells** - Cells produced by bone marrow to fight infection.

# *My Notes*





Southern Cross  
Health Trust

***With the support of Southern Cross we  
are able to reach more New Zealanders  
living with incurable breast cancer***



**Pub Charity**<sup>TM</sup>  
THE HEART OF COMMUNITY FUNDING

The background of the entire page is a light pink floral pattern. A large, stylized flower is centered in the upper half. The word 'SWEET' is in a simple, uppercase, sans-serif font, and 'Louise' is in a large, elegant, cursive script font, both in a dark pink color.

# SWEET *Louise*

For more information, visit [www.sweetlounge.co.nz](http://www.sweetlounge.co.nz)  
email [members@sweetlounge.co.nz](mailto:members@sweetlounge.co.nz)  
or call toll free (within New Zealand) on 0800 11 22 77.